

This electronic thesis or dissertation has been downloaded from the King's Research Portal at <https://kclpure.kcl.ac.uk/portal/>



PRE-REGISTRATION NURSES' REFLECTIONS ON LEARNING END-OF-LIFE-CARE:A FOCUS GROUP STUDY

Hawkins, Sian Anna

*Awarding institution:*  
King's College London

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without proper acknowledgement.

#### END USER LICENCE AGREEMENT



**Unless another licence is stated on the immediately following page** this work is licensed

under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International

licence. <https://creativecommons.org/licenses/by-nc-nd/4.0/>

You are free to copy, distribute and transmit the work

Under the following conditions:

- Attribution: You must attribute the work in the manner specified by the author (but not in any way that suggests that they endorse you or your use of the work).
- Non Commercial: You may not use this work for commercial purposes.
- No Derivative Works - You may not alter, transform, or build upon this work.

Any of these conditions can be waived if you receive permission from the author. Your fair dealings and other rights are in no way affected by the above.

#### Take down policy

If you believe that this document breaches copyright please contact [librarypure@kcl.ac.uk](mailto:librarypure@kcl.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.

**PRE-REGISTRATION NURSES' REFLECTIONS ON  
LEARNING END-OF-LIFE-CARE:  
A FOCUS GROUP STUDY**

**By**

**Sian Anna Hawkins**

**Doctorate in Health Care 2016**

## **Abstract**

The End-of-Life Care Strategy (DH 2008), Quality Standards for End-of-Life Care for Adults (NICE 2013) and One Chance to Get it Right (LACDP 2014), expect nurses to provide compassionate care with sensitive communication to the dying and their relatives. However, More Care Less Pathway reported examples of less than optimum care and communication (DH 2013). There has been a call for basic knowledge of end-of-life care to be in pre-registration nurses' programmes, but there are currently no curricula guidelines (DH 2008, 2013). Therefore, this study aimed to explore undergraduate pre-registration nurses' perceptions of how learning end-of-life-care could be enhanced in the Higher Education Institute (HEI) and Clinical Learning Environments (CLE).

A review into the effect of pre-registration nurses' education on end-of-life-care revealed eleven quasi-experimental studies. These suggest that following education programmes, knowledge and attitude towards end-of-life-care appeared to improve. However, only one study occurred in England. A meta-ethnography into pre-registration nurses' experiences of providing end-of-life-care revealed its emotional impact, including grief, anxiety and fear. This was influenced by ward culture, type of death, performing last offices, difficult communication with patients and relatives and support from friends and nurses. However, these studies did not explore pre-registration nurses' perceptions of factors that enhance how they learn to provide end-of-life-care.

A qualitative investigation was undertaken using focus group methodology. Twelve final year BSc Nursing (Adult) pre-registration students participated in three focus group interviews. Transcripts were analysed following techniques recommended by Strauss and Corbin (1998), including constant comparison, open, axial, selective and process coding. Five key elements that enhanced pre-registration nurses learning were elucidated: translation of knowledge between the HEI, CLE and P-RNs; role modelling; P-RNs motivation to learn, being able to manage the emotional labour of EOLC and the creation of a safe learning environment. It is recommended that future research should be directed towards a longitudinal study following pre-registration nurses learning during the programme, at six months and 12 months after qualification to reveal how knowledge is translated into end-of-life-care.

## **Acknowledgements**

I would like to thank my supervisors Dr Jo Armes and Dr Jaqualyn Moore for the help and guidance throughout the study. I would not have managed to complete this without their advice and encouragement. Also to my personal tutor Dr Julia Roberts whose unfailing support helped me through the first four years of the Doctorate in Health Care (Nursing) and the Programme Lead Dr Jocelyn Cornish for her invaluable advice. I am very grateful to Mark, Malene and Lily Gregory who have lent me their house to sit in to write the chapters. In addition Dr Marion Garnett, who has been a supportive friend over the years. Finally my husband Rod, son Aled and brother Owen who have been there for me when times have been challenging.

<b>Table of Contents</b>	<b>Page</b>
<b>Abstract</b> .....	<b>02</b>
<b>Acknowledgements</b> .....	<b>03</b>
<b>Abbreviations</b> .....	<b>13</b>
<b>Chapter 1 Introduction</b> .....	<b>15</b>
Personal interest.....	15
The organisation of the thesis.....	16
Definitions.....	17
Political and educational drivers towards pre-registration education in end-of-life-care.....	18
The development of end-of-life-care in England.....	18
Educational guidelines on learning end-of-life-care.....	21
Pre-registration nurse education in end-of-life-care in the curriculum.....	22
Summary.....	22
<b>Chapter 2 Focused review of educational strategies in end-of-life-care for pre-registration nurses</b> .....	<b>23</b>
Introduction.....	23
Method.....	23
Inclusion and exclusion criteria.....	25
Results of the systematic search.....	25
Description and methodological quality of the studies.....	25
Study designs.....	27
Sample size.....	33
Educational interventions and locations.....	33
Outcome measures.....	34
Findings.....	36
Attitudes towards end-of-life-care.....	36
Knowledge.....	39
Behaviour.....	40
Influence of age, gender and previous experience.....	41
Stage of programme.....	41
Discussion.....	42
Limitations of the studies and review.....	45
Summary.....	45

<b>Table of Contents</b>	<b>Page</b>
<b>Chapter 3 Pre-registration nurses' experiences providing</b>	
<b>end-of-life-care: A meta-synthesis.....</b>	<b>47</b>
Introduction .....	47
Defining meta-synthesis .....	47
The advantages of a meta-synthesis.....	47
Brief critique of meta-synthesis .....	49
Rationale for choosing meta-ethnography.....	51
The method .....	52
Phase 1. Getting started.....	52
Phase 2. Deciding what is relevant .....	54
Locating relevant studies .....	54
Inclusion exclusion criteria .....	55
Results .....	55
Critique for quality .....	58
Study settings and designs .....	60
Phase 3. Reading the studies .....	61
Phase 4. Determining how the studies are related.....	61
Phase 5. Translating the studies into one another .....	61
Phase 6. Synthesizing translations .....	62
What are pre-registration nurses' preconceptions'	
about end-of-life-care? .....	62
What are pre-registration nurses' experiences	
of end-of-life-care? .....	64
<i>Culture that promotes good death</i> .....	64
<i>Culture that allows a poor death</i> .....	64
<i>Emotional impact upon P-RNs</i> .....	66
<i>Reasons for the emotional reaction</i> .....	68
<i>Communication with patients and family members</i> .....	70
<i>Performing last offices</i> .....	70
Where do pre-registration nurses receive support when	
providing end-of-life-care? .....	73
<i>Ways of supporting P-RNs</i> .....	73
<i>Lack of support for P-RNs</i> .....	73

<b>Table of Contents</b>	<b>Page</b>
<b>Chapter 3</b>	
What are the rewards for pre-registration nurses when caring for the dying? .....	75
<i>Learning experience</i> .....	75
<i>Strategies that may improve the student experience</i> .....	75
Phase 7. Expressing the synthesis .....	77
Limitations to the meta-ethnography.....	81
Gaps in knowledge .....	81
Summary .....	83
<b>Chapter 4 Method</b> .....	<b>84</b>
Introduction .....	84
Research aim and objectives .....	84
Research design: Focus group methodology.....	84
Rationale for focus group methodology .....	86
Sample recruitment.....	89
Sample selection: homogeneous or heterogeneous.....	89
Sampling techniques.....	90
Exclusion criteria.....	90
Recruitment: maximising response and reducing coercion .....	91
Data collection .....	92
Demographic data.....	92
Topic guide development.....	92
Focus group size.....	92
Moderator's role.....	94
Ethical issues .....	97
Researcher/lecturer and participant relationship.....	98
Informed consent, the right to withdraw, autonomy and confidentiality.....	98
Potential harm and managing participants' distress.....	99
Protocol to manage disclosures of criminal activity or misconduct.....	99
Risk to the organisation and lecturer.....	99
Data analysis .....	100
Management of transcripts .....	100

<b>Table of Contents</b>	<b>Page</b>
<b>Chapter 4</b>	
Overview of constant comparison data analysis .....	101
Open coding and open memos .....	103
Axial coding and axial memos.....	105
Selective coding.....	114
Selecting quotations.....	115
Criteria for judging the study .....	116
Summary.....	119
<b>Chapter 5 Findings .....</b>	<b>120</b>
Introduction .....	120
Participants' characteristics.....	120
Focus group characteristics .....	120
Experience of end-of-life-care gained before the BSc programme .....	120
Placements where participants provided end-of-life-care .....	121
End-of-life-care in the curriculum .....	122
Overview of the findings.....	124
Category: Learning to manage expected and unexpected death .....	127
Subcategory: Learning to manage expected and unexpected death: Context of learning .....	127
<i>Property: Learning the theory of EOLC in the HEI</i> .....	127
<i>Property: Learning EOLC in the CLE</i> .....	129
Subcategory: Learning to manage expected and unexpected death: Registered nurse role model/mentor strategies .....	132
<i>Property: Registered nurse RM/M guided reflection to     learn to manage expected and unexpected death and the     potential emotional impact versus no guided reflection</i> .....	132
<i>Property: Registered nurse RM/M explained procedure     during resuscitation versus no explanation</i> .....	136
Subcategory: Learning to manage expected and unexpected death. Pre-registration nurses' characteristics and strategies.....	137
<i>Property: Potential emotional impact of expected and     unexpected death due to age and previous experience</i> .....	137



<b>Table of Contents</b>	<b>Page</b>
<b>Chapter 5</b>	
<i>Property: Strategies to manage the emotional impact of expected and unexpected death versus no strategies</i> .....	138
Category: Learning to communicate with the dying and their relatives.....	144
Subcategory: Learning to communicate with the dying and their relatives. Context of learning.....	144
<i>Property: Learning the theory of communication in the HEI</i> .....	144
<i>Property: Prepared for conversations versus unprepared in the CLE</i> .....	146
Subcategory: Learning to communicate with the dying and their relatives. Registered nurse/mentor enhances versus inhibits learning communication .....	148
<i>Property: Registered nurse/mentors' strategies that enhance learning compassionate communication</i> .....	148
<i>Property: Registered nurse/mentors' strategies that inhibit learning compassionate communication</i> .....	150
Subcategory: Learning to communicate with dying and their relatives. Pre-registration nurses' characteristics and strategies that enhance or inhibit learning.....	152
<i>Property: Younger versus older and previous experience versus no previous experience of EOLC</i> .....	153
<i>Property: Self-directed learning to communicate with the dying and their relatives</i> .....	154
Category: Learning to perform last offices .....	158
Subcategory: Learning to perform last offices. Context of learning .....	158
<i>Property: Theory of performing last offices in the HEI</i> .....	158
<i>Property: Performing last offices in the CLE</i> .....	159
Subcategory: Learning to perform last offices. Registered nurse/mentor strategies that enhance versus inhibits learning ....	160
<i>Property: No opportunity to practice last offices, RM/M did not explain procedure or provide guided reflection</i> .....	160
<i>Property: RM/M explains procedure and provides guided reflection</i> .....	161

<b>Table of Contents</b>	<b>Page</b>
<b>Chapter 5</b> Subcategory: Pre-registration nurses characteristics that enhances versus inhibits learning to perform last offices.....	162
<i>Property: Younger versus older participants and</i>	
<i>Previous experiences performing last offices versus</i>	
<i>no experiences of last office .....</i>	162
<i>Property: Self-directed learning to perform last offices .....</i>	162
Synthesis of factors that enhance and inhibit pre-registration nurses learning end-of-life-care .....	164
Summary.....	167
<b>Chapter 6 Discussion.....</b>	<b>168</b>
Introduction .....	168
Summary of the findings: enhancing P-RNs learning knowledge and skills in end-of-life-care.....	168
Translation of knowledge in end-of-life-care .....	171
Scaffolding support for learning end-of-life-care .....	174
Sequencing of theory and practice and the theory-practice gap .....	177
Aspects of the clinical learning environment and the theory-practice gap .....	180
Learning through role modelling.....	181
Motivation to learn end-of-life-care.....	184
Learning to manage the emotional labour of end-of-life-care.....	187
The effect of emotional upset upon the learning process.....	189
Developing strategies to manage the emotional impact of providing EOLC.....	191
Promoting a safe learning environment .....	193
Summary.....	195
Limitations and strengths of this study .....	195
<b>Chapter 7 Conclusion and recommendations .....</b>	<b>197</b>
Overview of findings.....	197
Recommendations for nursing education.....	199
Recommendations for clinical practice.....	200
Future research.....	201
<b>References .....</b>	<b>203</b>

<b>Table of Contents</b>	<b>Page</b>
<b>Appendix</b>	
<b>Appendix 1</b>	Comparison of domains for education in end-of-life-care ..... 227
<b>Appendix 2</b>	Outcome measurement tools validity and reliability ..... 231
<b>Appendix 3</b>	Permission from Head of Faculty ..... 233
<b>Appendix 4</b>	Ethical approval letter ..... 234
<b>Appendix 5</b>	Recruitment email ..... 235
<b>Appendix 6</b>	Information sheet for participants ..... 236
<b>Appendix 7</b>	Consent form ..... 238
<b>Appendix 8</b>	Background questionnaire ..... 239
<b>Appendix 9</b>	Topic guide ..... 241
<b>Appendix 10</b>	Reflection: Role of researcher/lecturer ..... 243
<b>Appendix 11</b>	Sample of open coding for FGA (excerpt) ..... 244
<b>Appendix 12</b>	Reflection: Learning from personal bereavement ..... 245

### **Table of Figures**

<b>Figure 2.1</b>	Flowchart of search results for how effective are educational strategies for learning EOLC ..... 26
<b>Figure 3.1</b>	Flowchart of search results for pre-registration nurses' experiences of EOLC ..... 56
<b>Figure 3.2</b>	Pre-registration nurses' experiences of EOLC: a conceptual map ..... 78
<b>Figure 4.1</b>	An early diagram mapping the trajectory of linear learning EOLC ..... 113
<b>Figure 5.1</b>	Factors that enhance and inhibit learning EOLC: a conceptual map ..... 165
<b>Figure 6.1</b>	Factors that enhance P-RNs learning EOLC ..... 170
<b>Figure 6.2</b>	Comparisons of Maslow's Hierarchy of Needs and the Ascent to Competence ..... 193

<b>Table of Tables</b>		<b>Page</b>
<b>Table 2.1</b>	Data bases searched .....	24
<b>Table 2.2</b>	Quantitative search terms.....	24
<b>Table 2.3</b>	Studies evaluating education strategies among pre-registration nurses .....	28
<b>Table 2.4</b>	ReLIANT: appraisal framework .....	32
<b>Table 2.5</b>	Outcome measures for attitude .....	35
<b>Table 2.6</b>	Outcome measures for knowledge .....	35
<b>Table 2.7</b>	Outcome measures for behaviour .....	36
<b>Table 3.1</b>	Comparison of meta-synthesis .....	48
<b>Table 3.2</b>	Phases of meta-ethnography .....	53
<b>Table 3.3</b>	Qualitative search terms.....	54
<b>Table 3.4</b>	Qualitative studies in the meta-ethnography .....	57
<b>Table 3.5</b>	CASP Ten questions to help you make sense of qualitative research .....	59
<b>Table 3.6</b>	Metaphors for preconceptions .....	63
<b>Table 3.7</b>	Metaphors for culture that promotes good death.....	65
<b>Table 3.8</b>	Metaphor for culture that allows a poor death .....	65
<b>Table 3.9</b>	Metaphors for the emotional impact upon P-RNs.....	67
<b>Table 3.10</b>	Metaphors for the reasons for the emotional reaction .....	69
<b>Table 3.11</b>	Metaphors for communication with patients and their family members .....	71
<b>Table 3.12</b>	Metaphors for performing last offices .....	72
<b>Table 3.13</b>	Metaphors for ways of supporting P-RNs.....	74
<b>Table 3.14</b>	Metaphors for lack of support for P-RNs .....	74
<b>Table 3.15</b>	Metaphors for learning experience .....	76
<b>Table 3.16</b>	Metaphors for strategies that may improve the student experience .....	76
<b>Table 4.1</b>	Open codes-extensiveness .....	107
<b>Table 4.2</b>	A1 Emily: Learning enhanced and inhibited before and during the programme .....	109
<b>Table 4.3</b>	Open codes compared to difficult conversations and previous experiences in EOLC example.....	110
<b>Table 4.4</b>	Example of comparing findings to theories and literature .....	112
<b>Table 5.1</b>	Participants age, gender, codes and pseudonyms.....	121

<b>Table of Tables</b>		<b>Page</b>
<b>Table 5.2</b>	Experience of end-of-life-care before programme .....	121
<b>Table 5.3</b>	NHS Trusts.....	122
<b>Table 5.4</b>	Where participants provided EOLC during the BSc programme .....	123
<b>Table 5.5</b>	Learning end-of-life-care in the curriculum .....	124
<b>Table 5.6</b>	Core category, categories and properties with data source....	126

<b>Table of Text Boxes</b>		<b>Page</b>
<b>Text Box 4.1</b>	Reflexivity during a focus group .....	95
<b>Text Box 4.2</b>	Open code memo example .....	104
<b>Text Box 4.3</b>	Axial memo: Conditions, actions and consequences .....	106
<b>Text Box 4.4</b>	Axial memo.....	111
<b>Text Box 4.5</b>	Process memo .....	112
<b>Text Box 4.6</b>	Example of a descriptive story line .....	114

## Abbreviations

AACEL	Attitudes About Care at the End of Life
AACN	American Association of Colleges of Nursing
A&E	Accident and Emergency Department
CACDP	Concerns About Caring for Dying Patients
CASP	Critical Appraisal Skills Programme
CASP-RCT	Critical Appraisal Skills Programme 'Ten questions to help make sense of randomised control trials'
CCC	Core Competencies and Principles for Health and Social Care Workers Working with Adults at the End of Life
CG	Control Group
CLE	Clinical Learning Environment
CNS	Clinical Nurse Specialist
CPR	Cardio-Pulmonary Resuscitation
DH	Department of Health
EAPC	European Association of Palliative Care
ELNEC	End-of-Life Nursing Education Consortium
EOL	End-of-Life
EOLC	End-of-Life Care
EONS	European Oncology Nursing Society
ERM/M	Exceptional Role Model/Mentor
ESC	Essential Skills Cluster
FGA	Focus Group A
FGB	Focus Group B
FGC	Focus Group C
GMC	General Medical Council
GSF	Gold Standards Framework
HCA	Health Care Assistant
HEI	Higher Education Institution/University/College
HIV	Human Immunodeficiency Virus
ITU	Intensive Therapy Unit / Intensive Care Unit
LACDP	Leadership Alliance for the Care of Dying People
LCP	Liverpool Care Pathway
LOA	Line of Argument

NAO	National Audit Office
NCPC	National Council for Palliative Care
NHS TRUST	National Health Service Trusts and Foundation Trusts which pre-registration nurses are allocated to for clinical placements
NICE	National Institute for Health and Care Excellence
NMC	Nursing and Midwifery Council
NMC Standards	Nursing and Midwifery Council Standards for Proficiency for Pre-registration Nurses
OPD	Outpatient Department
PBL	Problem Based Learning
PCC4U	Palliative Care Curriculum for Undergraduates
PICO	Population Intervention Comparator/control Outcome
P-RN	Pre-Registration Nurse
P-RNs	Pre-Registration Nurses
RCN	Royal College of Nursing
RCT	Randomised Controlled Trial
ReLIANT	Researchers guide to the Literature on Interventions Addressing the Need for education and Training
RM/M	Role Model/Mentor
RN	Registered Nurse
RNs	Registered Nurses
RTA	Reciprocal Translation Analysis
SDL	Self-Directed Learning
SPIDER	Sample Phenomenon Design Evaluation Research
SPIKES	Setting Perception Invitation Knowledge Empathy Strategy/Summary
SRL	Self-Regulated Learning
UK	United Kingdom
UKCC	United Kingdom Central Council for Nursing, Midwifery and Health Visiting
USA	United States of America
WHO	World Health Organisation

## **Chapter 1 Introduction**

### **Personal interest**

My interest in researching how pre-registration nurses (P-RNs) learn to provide compassionate end-of-life-care (EOLC) emerges from sixteen years clinical experience caring for people with cancer and twenty years as a lecturer in pre-registration nursing. P-RNs' anecdotal stories reveal traumatic and rewarding experiences. Some felt supported; others unsupported in the clinical learning environment (CLE), some felt prepared and others unprepared by the Higher Educational Institute (HEI). This spurred my personal interest to improve the support and education of P-RNs. If nurse educators are to effectively prepare nurses to skilfully deliver EOLC it is necessary to know how they gain these skills and knowledge. Hence this research is grounded within clinical practice and teaching P-RNs end-of-life-care.

An important aspect of the role of a registered nurse (RN) is to provide EOLC for the dying and their relatives in hospitals, at home, residential homes and hospices. The Department of Health (DH) 'End-of-Life-Care Strategy' (DH 2008), aims to promote compassionate care for the dying in any healthcare setting. However, the 'First National Voices of Bereaved People' (DH 2012a), 'More Care Less Pathway: Review of the Liverpool Care Pathway' (DH 2013) and the 'National Care-of-the-Dying Audit for Hospitals England' (Royal College of Physicians and Marie Curie Cancer Care 2014) highlight inconsistencies in EOLC. Encouragingly these reports revealed examples of sensitive compassionate care when dying in hospices, at home, in residential homes, and hospitals. Conversely, poor communication and a lack of compassion with patients and relatives feeling abandoned were also reported (DH 2012a, 2013, Parliamentary and Health Service Ombudsman 2015). Thus, despite improvements there remains a deficit in EOLC.

The Department of Health (2008), called for basic knowledge and awareness of EOLC in all pre-registration education. In the United Kingdom (UK), the Nursing and Midwifery Council (NMC) requires P-RNs to:

'demonstrate that they are practising safely and effectively, have met the standards of proficiency and all other requirements to become registered' (NMC 2008a p45).



P-RNs learning occurs 50% in an HEI and 50% in the clinical learning environment (CLE). P-RNs are supernumerary in the CLE and aim to work for 40% of the placement with a mentor who is a RN who has completed the mentorship course. The aim is to develop a nurse who is fit to practice with the knowledge, attitudes and skills to care for patients (NMC 2008a). More recently, 'Compassion in Practice' (DH 2012b) recommends the implementation of the 6C's (care, compassion, competence, communication, courage, commitment) in the care of all patients including the dying. This integrates with 'Quality Standards for End-of-Life Care for Adults' (NICE 2013) and 'One Chance to Get it Right' (LACDP 2014). These guidelines focus on health professionals communicating sensitively with patients and relatives to create individual care plans. However, there are no statements explicitly relating to P-RNs' learning EOLC in England.

Research into P-RNs' perceptions of their training programme reveals EOLC can be distressing (Timmins & Kaliszer 2002, Evans & Kelly 2004, Costello 2006, Cunningham et al 2006, Higgins et al 2006). RNs reported their pre-registration training did not prepare them for EOLC (NAO 2008). Therefore, it is pertinent to explore P-RNs' perceptions of how learning EOLC could be enhanced.

### **The organisation of the thesis**

In order to provide the context for the research this chapter will explore political and educational drivers for P-RNs learning EOLC. This is followed by a review of the effectiveness of education initiatives in preparing P-RNs to deliver EOLC in Chapter 2. Chapter 3 is a meta-synthesis of P-RN's experiences of EOLC and contains a summary of the gaps in knowledge that stimulated this investigation. Chapter 4 describes the qualitative methodology used, focus groups and provides examples of data analysis. In addition, ethical considerations and methods to promote rigor are explained. Chapter 5 presents the findings; these are discussed in Chapter 6 in relation to the aim and objectives, theories of learning and published literature. Finally, Chapter 7 concludes by considering the limitations of the study and recommendations made for changes in P-RNs' education in the HEI and CLE. In this thesis the third person is predominantly used, however, the first person will be used when

discussing reflexivity. The terms, 'my study,' 'my findings,' 'this investigation' and 'this thesis' explicitly distinguish this doctoral research from other studies.

## **Definitions**

In order to guide the reader, definitions related to P-RNs and end-of-life-care are provided along with personal definitions used to frame this research. As nurses in the UK are regulated by the NMC, their definitions were adopted where appropriate.

*Pre-registration nurses (P-RNs)* are undertaking a Diploma or BSc in Nursing Studies with Registration to care for adults (NMC 2010a).

*Diploma nursing students* are undertaking a Diploma in Higher Education (Adult Nursing).

*Student* refers to any P-RN irrespective of the educational programme.

*Mentor* is 'a registered nurse or midwife on the NMC register who, following successful completion of an NMC approved mentor preparation programme, is entered on a local register and is eligible to supervise and assess students in a practice setting' (NMC 2010a p148).

*Qualified or registered nurse (RN)* are 'regulated by a statutory regulator such as the NMC' (NMC 2010a p148).

*Definitions of end-of-life-care* have evolved, over time resulting in a plethora of terms. Therefore the following framed this thesis:

*Palliative care* has traditionally referred to people dying from cancer and long term neurological conditions (NICE 2004). *End-of-Life Care* in the UK refers to anybody who is dying from cancer or non-cancer causes and is defined as:

'the provision of supportive and palliative care in response to the assessed needs of patient and family during the last phase of life' (DH 2008 p37).

Thus palliative and EOLC are terms used interchangeably that refer to the care-of-the-dying at home, in hospital, residential care homes, and hospice. The General Medical Council (GMC) supply a comprehensive definition of end-of-life-care:

‘People whose death is imminent (expected within the few hours or days) and those with advanced, progressive incurable conditions, general frailty and co-existing conditions that means they are expected to die within 12 months, existing conditions if they are at risk of dying from a sudden acute crisis in their condition and life-threatening acute conditions caused by sudden catastrophic events’ (GMC 2010 p86).

The Leadership Alliance for the Care of Dying People (LACDP 2014) drew upon the ‘Guidelines for Supportive and Palliative Care’ (NICE 2004) and ‘Quality Standards for End-of-Life Care for Adults’ (NICE 2013) to create the five priorities for care-of-the dying in ‘One Chance to Get it Right’:

- ‘1. The possibility of dying is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion’ (LACDP 2014 p10).

In this thesis the terms EOLC and care-of-the-dying are used interchangeably to refer to expected and unexpected deaths.

## **Political and educational drivers towards pre-registration education in end-of-life care**

### The development of end-of-life-care in England

Before the 1950s people died in hospital, at home or in Homes for the Dying created by religious orders. Peoples’ pain and suffering were considered a ‘cross to bear’ (Humphreys 2001). In the mid-twentieth century the desire to promote dying with dignity was driven by four key events (Clark 1995). Firstly in 1958, Dame Cicely Saunders, a nurse, social worker and medical doctor, undertook research with patients’ at St Joseph’s Hospice. This resulted in the concept of ‘Total Pain;’ and the need for both symptom and psychological support (Saunders & Clark 2006). Secondly, sociologists Glaser and Strauss (1965) identified a ‘conspiracy of silence,’ in which relatives knew the diagnosis and prognosis but patients were not told. They recommended moving towards

an 'open awareness' of dying between doctors, patients and relatives. Thirdly, Kubler-Ross (1970), a psychiatrist in Chicago USA, researched the experiences of dying patients and their relatives'. This led to the development of 'The Stages of Dying' model which contributed to a greater understanding of the effects of grief and loss and the development of strategies to support the dying and bereaved. Fourthly, Dame Cicely Saunders drew these concepts into the principles that still underpin EOLC in the modern hospice movement: symptom management; give patient analgesia when in pain; support the whole person and their relatives; open awareness and truthfulness with the patient and relatives; multi-professional team approach; and bereavement care (Saunders & Clark 2006).

Investigations into patients and carers wishes revealed patients wished to die at home rather than in hospital (Higginson 2003, NCPC 2005a). However, when family are unable to manage the physical deterioration of their relative's 'unbounded body' due to incontinence and fungating wounds, these people are more likely to be admitted into a hospital or hospice (Lawton 2000 p123). A UK national survey of carers revealed those who had relatives with cancer received more information and support than those without cancer (Beaver et al 2000, Burt 2010). This may be due to palliative care nurses developing close and often sustained contact with patients with cancer and their relatives. They have developed advanced psychosocial skills to support people living with the repercussions of a life-limiting illness and have a significant degree of autonomy from medical teams (Field and Copp 1999, Corner et al 2002). Conversely, relatives described care in surgical wards and critical care as being rushed and where nurses avoided them so they felt unsupported (Bridgeman & Carr 1997, Wakefield 1999, Dunne & Sullivan 2000, Attree 2001). In contrast; hospice nurses considered the support of the patient and family a priority (Johnson & Smith 2006, Ablett & Jones 2007).

The period 2008-2016 has seen the principles of palliative care integrated into the care of everyone who is dying. The National Council for Palliative Care (NCPC) explored care-of-the-dying among older people (NCPC 2005b) and those with dementia (NCPC 2006a), heart failure (NCPC 2006b), neurological conditions (NCPC 2006c) and respiratory disease (NCPC 2008). Recommendations to improve palliative care for everyone were made in '20:20

vision: The Shape of the Future for Palliative Care' (NCPC 2005c) and 'Changing Gear Guidelines for Managing the Last Days of Life in Adults' (NCPC 2006d). These were operationalised by the 'End-of-Life Care Strategy' (DH 2008) and 'Quality Standards for End-of-Life Care for Adults' (NICE 2013). These principles of palliative care were disseminated through the 'Liverpool Care Pathway' (LCP) (Ellershaw & Wilkinson 2003), 'Gold Standards Framework' (GSF 2010, 2012) and 'Advanced Care Planning' (Marie Curie Cancer Care 2013).

The LCP was heavily criticised in national newspapers between 2012 and 2013 with examples of dehydration, malnutrition and poor communication with families. Despite professional support for the LCP, there was limited research to refute these claims (DH 2012a, Costantini et al 2013). In addition the 'First National VOICES Survey of Bereaved People' (DH 2012a) collated the experiences of 22,292 relatives bereaved in the previous 12 months. This concluded that the quality of care varied. Dignity and respect were most often provided in hospices (80%), by General Practitioners, (72%) and in care homes (61%), but were less frequently demonstrated by hospital doctors (57%) and nurses (48%). A review of complaints in 16 hospitals revealed relatives were not aware of approaching end-of-life, poor communication during the breaking of bad news, inconsistent messages and feeling isolated or abandoned. In addition, poor symptom management, not enough privacy and poor fundamental medical and nursing care was reported (Neuberger 2013).

As a result 'More Care Less Pathway' concluded that when the LCP was correctly implemented, compassionate high quality care was delivered but there were 'serious cases of unacceptable care where people were treated with less dignity and respect than they deserve' (DH 2013 p3). It was recommended that health professionals develop knowledge of the essential principles of good care, communication skills and decision making. Furthermore, it was proposed that there needs to be organisational leadership in prioritising EOLC (Sykes 2013).

The LCP was replaced with 'One Chance to Get it Right' (LACDP 2014). This set out five priorities, based on individualised care-of-the-dying and focused on sensitive communication with patients and relatives. These align with the 6C's of care, compassion, competence, communication, courage and commitment

(DH 2012b) and the Quality and Standards for End-of-Life-Care for Adults (NICE 2013). However, the report 'Dying without dignity' highlighted continued complaints about symptom management and poor communication (Parliamentary and Health Service Ombudsman 2015). These documents make it clear that delivery of high quality EOLC is a priority for health services and as RNs are the professional group most heavily involved in providing EOLC, it is relevant to explore the educational drivers for P-RNs to learn to care-of-the-dying.

#### Educational guidelines on learning end-of-life-care

Pre-registration education in EOLC has been recommended by NICE (2004, 2013) and the DH (2006, 2008, 2013). The European Association for Palliative Care (EAPC) developed a palliative care curriculum for P-RNs and RNs working in general health care settings, as well as advanced practitioners and specialist nurses who work in palliative care settings, oncology, paediatrics and elderly care (De Vliegner et al 2004a,b). The domains focus on the patient, family, interdisciplinary team, self-awareness/ethical issues, death in society, palliative care in the healthcare system, training in palliative care research and training for educators in palliative care.

In England there is no explicit guidance on how P-RNs should learn to provide EOLC. Instead the 'End-of-Life Care Strategy' (DH 2008) states the components of the NMC (2004) 'Pre-registration Standards for Proficiency for Pre-registration Nurses' (NMC Standards) and the 'NMC Essential Skills Clusters' (ESC) can be applied to end-of-life-care (NMC 2008b). In contrast in the care home sector the 'Common Core Competencies and Principles for Health and Social Care Workers Working with Adults at the End-of-Life' (CCC) have been developed to guide registered health professionals (DH 2009). These competencies were built around the domains of Communication Skills, Assessment and Care Planning, Symptom Management and Advanced Care Planning for the Preferred Places for Care. These were mapped against the NMC Standards, ESC and CCC and they were found to match with the EAPC Domains for Education in Palliative Care (Appendix 1).

RNs have identified that pre-registration education did not prepare them to provide EOLC and they consistently requested further education in symptom management, psychosocial support and communication skills (Bergen 1992,

Corner & Wilson-Barnett 1992, Fothergill-Bourbonnais & Wilson Barnett 1992, Wilkes et al 1998, Hopkinson et al 2003, Dunne et al 2005, NAO 2008).

### Pre-registration nurse education in end-of-life-care in the curriculum

P-RNs and newly qualified RNs are expected to care-for-the-dying, however guidance is lacking on what should be taught about EOLC and when. Research investigating the amount and type of education delivered in the pre-registration curriculum will now be reviewed. Two studies surveyed education on EOLC in HEIs in England (Lloyd-Williams & Field 2002, Dickenson et al 2008). The findings revealed variation; whereas some curricula included an explicit EOLC module, others integrated this subject throughout a selection of modules spread over three years and the hours allocated varied between two and 45 (Lloyd-Williams & Field 2002, Dickenson et al 2008). Neither study however, explored the effectiveness of different educational strategies on P-RNs' knowledge, skills and attitudes in the CLE. The surveys have not been repeated since the End-of-Life-Care Strategy (DH 2008) was implemented, so these findings may not reflect current education delivery.

### **Summary**

Care-of-the-dying is an important aspect of nursing care, however RNs have identified they do not receive enough end-of-life education during their pre-registration training (NAO 2008). In addition, the content and dedicated hours varies between HEIs (Lloyd-Williams & Field 2002, Dickenson et al 2008). This suggests that EOLC may not be sufficiently prioritised in pre-registration education. Therefore, this raises the question: How effective are educational strategies in preparing P-RNs for EOLC? This issue will be explored in the next chapter.

## **Chapter 2 Focused review of educational strategies in end-of-life-care for pre-registration nurses**

### **Introduction**

This chapter will review studies that evaluate education strategies for P-RNs learning EOLC. It was beyond the scope of this thesis to undertake a systematic review as the studies are not comparable due to differing educational methods and outcome measures. Therefore, a focused review was undertaken that used a systematic approach through a research question, systematic search for the evidence and quality appraisal of the studies. Data were extracted and a written synthesis of the findings was performed.

### **Method**

P-RNs provide EOLC in the CLE and are taught using a variety of methods in HEIs. Therefore a systematic search of the literature was performed between October 2013 and April 2014, to answer the question:

‘How effective are education strategies in preparing pre-registration nurses to deliver end-of-life-care?’

To be as comprehensive as possible the literature search followed recommendations made by Greenhalgh and Peacock (2010). A search of the grey literature revealed relevant policies, guidelines and expert opinions. Electronic databases may be incomplete and abstracts contain varying amounts of information, while search terms cannot identify all the evidence (Greenhalgh & Peacock 2010). Therefore a supplementary search of articles was conducted on publishers’ search engines and a review of the reference lists from each study and article was performed (Table 2.1).

Relying on any one search strategy may miss relevant records. Therefore a combination of search strategies using thesaurus, free text, broad based terms and Medical Subject Headings (MeSH) were utilised to maximise yield (Booth 2008). The core search strategy was developed using the SPIDER approach (Sample, Phenomenon (PI), Design, Evaluation, Research) as it appears to have greater sensitivity and specificity than PICO in identifying relevant quantitative, qualitative and mixed method research (Cooke et al 2012). Where appropriate search terms were combined with the Boolean operators ‘or’ to



maximise sensitivity as well as 'and,' to maximise specificity. Free text terms for quantitative research were used (Table 2.2).

Table 2.1 Data bases searched

Data bases	Grey literature	Journals	Publishers search engines
ASSIA, BNI, CancerLit, CINAHL, PLUS, EMBASE, MEDLINE, PsycINFO	American Association of Colleges of Nursing (AACN), Cancer Research UK, Department of Health, End-of-Life Nursing Education Consortium (ELNEC), End-of-Life Care Programme, European Association for Palliative Care, Gold Standard Framework, Marie Curie Cancer Care, Macmillan Cancer Support National Audit Office (NAO), National Institute for Health and Care Excellence, National Council for Palliative Care , Palliative Care for Curriculum for Undergraduate (PP4U) Palliative Care Observatory, World Health Organisation, World Wide Palliative Care Alliance	Clinical Simulation in Nursing, International Journal of Nursing Education Scholarship, International Journal of Palliative Nursing, Journal of Hospice and Palliative Nursing, Journal of Pain and Symptom Management, Palliative Medicine, International Journal of Palliative Nursing, Nurse Education in Practice, Nurse Education Today, Nurse Educator, Teaching and Learning in Nursing	Elsevier's Science Direct, Internurse, Wiley-Blackwell's Interscience

Table 2.2 Quantitative search terms

Sample: Student Nurses	Phenomenon: Palliative	Design: Data collection	Evaluation: Education	Research: Quantitative
Baccalaureate	Dead	Questionnaire	Assessment	Pre-test
BSc	Death	Survey	Course	Post-test
Degree	Dying		Curriculum	Quasi experimental
Diploma	End of Life		Education	Randomised Control Trial
Pre-registration	LCP		Knowledge	RCT
Nurse	Liverpool Care Pathway		Learn	Study
Nurses	Palliative		Module	
Student	Terminal		Modules	
Undergraduate			Programme	
			Simulation	
			Taught	
			Training	

### Inclusion and exclusion criteria

The following inclusion and exclusion criteria were applied.

#### Inclusion criteria:

- Evaluated P-RNs' educational strategies for learning EOLC
- Written in English from UK, Europe, USA, Canada and Australia as these have similar health care systems and integrated palliative and end-of-life care in general health care settings (Clark & Wright 2007)
- Conducted between 1986 and 2014, as quantitative studies before 1986 were deemed too old for temporal relevancy due to innovations in nursing practice and the movement to diploma/degree university based education in the UK from 1986 (UKCC 1986)

#### Exclusion criteria:

- Publications related to symptom management or disease pathology
- Quantitative/qualitative research into the education of doctors, allied health professionals, health care assistants, RNs and P-RNs undertaking child or mental health branch, as their perspectives may be different to P-RNs caring for adults
- Quantitative studies into P-RNs' attitudes towards death as these may not reveal nurses' experiences of caring for the dying
- Descriptive evaluations of EOLC educational initiatives
- Surveys of EOLC content in P-RNs programmes

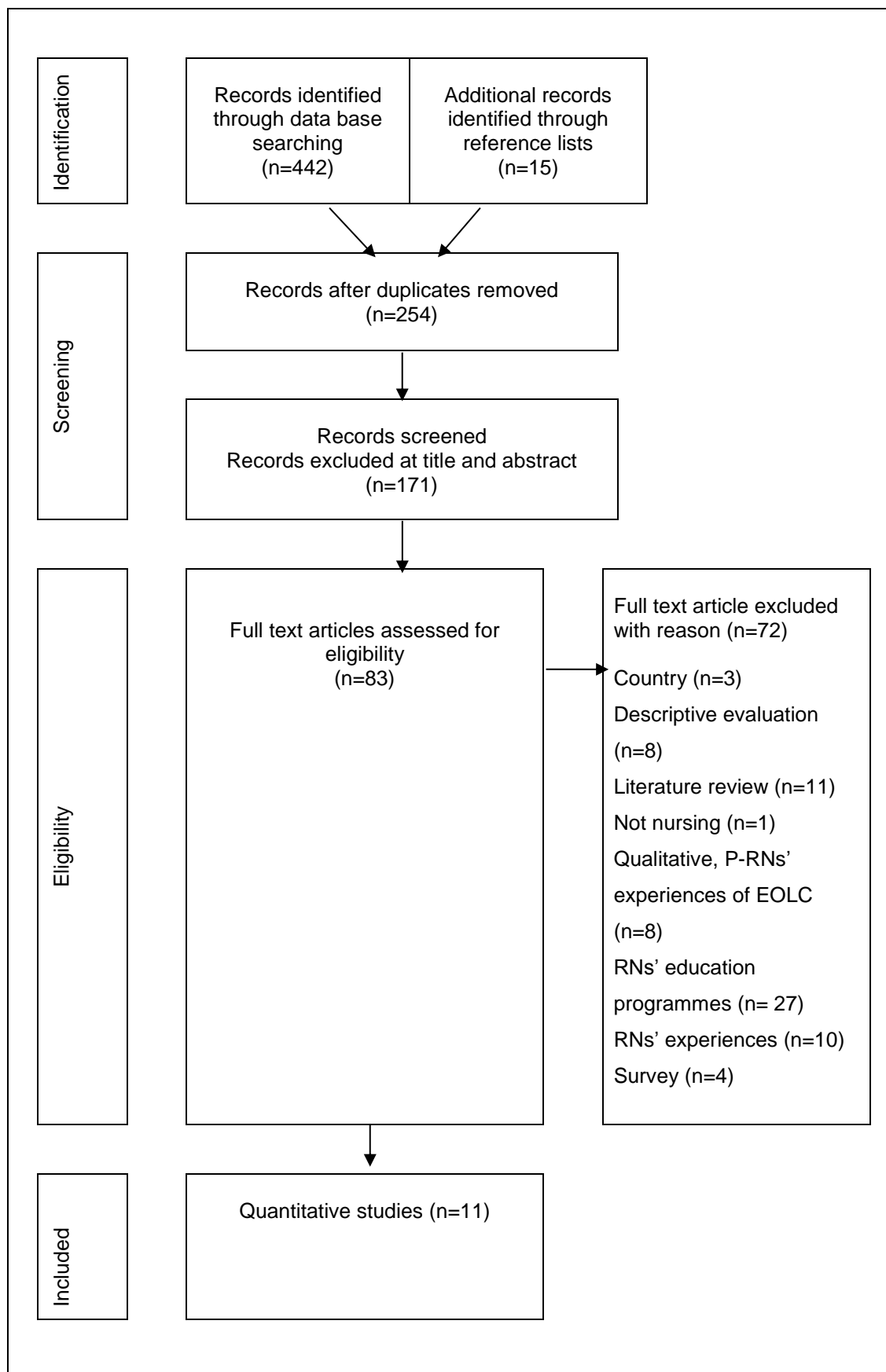
### Results of the systematic search

A total of 457 records were found, this reduced to 254 after the duplicates were removed (Figure 2.1). Each abstract was assessed against the inclusion and exclusion criteria and the full research report read if it explored the education of P-RNs in EOLC. Eleven quantitative studies were retained, assessed for quality and the findings reviewed.

### Description and methodological quality of the studies

Eleven quasi-experimental or pre-test-post-test, studies were retained (Degner & Gow 1988, Arber 2001, Mallory 2003, Kwekkeboom et al 2005, 2006, Barrere et al 2008, Dobbins 2011, Weissman 2011, Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). An overview of each study's design, findings and

Figure 2.1 Flowchart of search results for how effective are educational strategies for learning EOLC



limitations are presented in Table 2.3. Each study was appraised for methodological strengths and weaknesses in order to place the findings into perspective and make clear the limitations of the knowledge generated. Finding a suitable critical appraisal tool was challenging as 'little emphasis has been given to critically appraising educational research in healthcare' (Brice & Carlson 2004 p3). The Researchers guide to the Literature on Interventions Addressing the Need for Education and Training (ReLIANT) appraisal tool was selected (Koufogiannakis et al 2006). This was based on the Critical Appraisal Skills Programme 'Ten questions to help you make sense of randomized control trials' (CASP-RCT) (Public Health Resources Unit 2013). It incorporates the CASP-RCT components of validity (study design), reliability (results) and applicability (relevance). In addition ReLIANT was shown to be a valid and reliable tool to appraise educational research (Koufogiannakis et al 2006). The eleven studies were mapped against ReLIANT (Table 2.4).

### Study designs

All studies selected quasi-experimental designs, as the educational strategies were either optional or compulsory and so participants could not be randomised (Cohen et al 2011) (Table 2.3 & 2.4). Some studies selected the intervention and control groups from the same university which increased the risk of contamination through discussion between the groups (Kwekkeboom et al 2005, 2006, Dobbins 2011). Degner and Gow (1988), Mallory (2003) and Weissman (2011) used a blind control group from another university to reduce selection bias and contamination and enhance the validity of the findings.

Non-randomised studies are strengthened by matching groups to be as similar as possible, as substantial differences may reduce the findings' validity (Greenhalgh 2010, Cohen et al 2011). Half the studies matched the intervention and control groups for stage and type of programme (Degner & Gow 1988, Kwekkeboom et al 2005, 2006, Mallory 2003, Barrere et al 2008, Weissman 2011). However, equivalency matching for gender, age, previous education and EOLC experience was not always possible due to varying characteristics and post-test attrition rates (Degner & Gow 1988, Kwekkeboom et al 2005, 2006, Mallory 2003, Barrere et al 2008, Weissman 2011). In addition, there was a limited discussion about matched groups by Dobbins (2011). In the remaining studies a single group pre-test-post-test design was selected when a control

Table 2.3 Studies evaluating education strategies among pre-registration nurses

Authors/year/country/aim	Methodology/method	Sample	Findings	Limitations
<p><b>1. Degner &amp; Gow (1988) Canada</b> Evaluate the effectiveness of preparing nurses for care-of-the-dying; through an integrated programme or a module with clinical practice</p>	<p>Longitudinal quasi experimental IG: O<sub>1</sub> X O<sub>2</sub>O<sub>3</sub> CG1: O<sub>4</sub> X O<sub>5</sub>O<sub>6</sub> CG 2: O<sub>7</sub>O<sub>8</sub> Pre-test-post-test end of year, Second post-test one year after qualification (n= 170, 51.5%) Intervention: CG1: EOLC integrated in a programme (theory-6 hours), IG module (theory-72 hours) and hospice/ cancer unit (one day/week) Outcome measure: Collette-Lester Fear of Death Scale; WQUDDPF; Interviews</p>	<p>Total= 270 IG: 102 third year undergraduate nurses CG1: 94 third year undergraduate nurses CG2: 73 home economics students IG and CG1 from different universities</p>	<p>1. Death Anxiety: At post-test there was a greater reduction among IG (t=2.14, p=0.033), suggesting this was due to education programme 2. No differences in death anxiety between IG and CG1 one year post qualification (p=0.76) 3. Attitude: IG and CG1 improved. The difference between the groups was not significant suggesting it was not due to the intervention 4. IG maintained better attitudes between post-test and second post-test than CG1. It took longer for CG to converge with the levels of IG at post-test one 5. Behaviour: Second post-test-IG perceived they were more prepared to talk with patients and refer to other professionals</p>	<p>1. Post-test selection bias as those attending may have an interest in care-of-the-dying 2. Attrition post-test (IG n=51/102, CG1 n=40/91) 3. CG2 non-nursing may lead to an erroneous conclusion that the intervention is effective 4. Death anxiety decreases with increasing age and experience in nursing, thus maturation may be mistaken for treatment effect</p>
<p><b>2. Arber (2001) England UK</b> Evaluate a palliative care module for third year nursing students knowledge</p>	<p>Quasi experimental O<sub>1</sub> X O<sub>2</sub> Single group Pre-test-post-test last day Intervention: Module (theory-50 hours), hospice placement (5 days) Outcome measure: PCQN</p>	<p>Total= 33 third (final) year undergraduate.</p>	<p>1. Knowledge: Statistically significantly increase in understanding (p=0.001) 2. Did not increase understanding of side effects of codeine and sedation</p>	<p>1. Small sample size 2. Selection bias as volunteered 3. Unknown effect on behaviour 4. Unknown if knowledge retained when qualified 5. Post-test attrition n=12/45</p>
<p><b>3. Mallory (2003) USA</b> Assess the impact of a palliative care educational component on the attitudes toward care-of-the-dying in undergraduate nursing students</p>	<p>Quasi-experimental IG: O<sub>1</sub> X O<sub>2</sub>O<sub>3</sub> CG: O<sub>4</sub> O<sub>5</sub> Pre-test-post-test (1 &amp; 4 weeks) Intervention: IG ELNEC module (8 weeks) CG: no EOLC education Outcome measure: FATCOD</p>	<p>Total= 95 third year (junior) undergraduate IG: 41 CG: 54 IG and CG at different universities</p>	<p>1. Attitude: Significant difference between IG and CG FATCOD Scores (p&lt; .05) CG did not have a statistically significant change in attitude (p= .181) 2. Retained positive attitudes 4 weeks second post-test 3. Trend towards a relationship between previous deaths experience and attitude. 4. Previous education did not influence attitude</p>	<p>1. CG received unplanned education about end-of-life care and grief 2. Potential bias as researcher was teacher 3. Hours for intervention is unknown 5. Attrition post-test (IG n=4/45), second-post-test (IG n=9/45, CG n=5/59)</p>

Table 2.3 Studies evaluating education strategies among pre-registration nurses

Authors/year/country/aim	Methodology/method	Sample	Findings	Limitations
<p><b>4. Kwekkeboom et al (2005) USA</b> Evaluate the effect of a Palliative Care Companion programme on undergraduate nursing students knowledge and attitudes</p>	<p>Quasi experimental IG: O<sub>1</sub> X O<sub>2</sub> CG: O<sub>3</sub> O<sub>4</sub> Pre-test-post-test (4 months) Intervention: orientation, attend seminars in hospice and talk with the dying (15 weeks) Outcome measure: PCQN; AACEL; CACDP</p>	<p>Total= 34 Baccalaureate, year not given. CG: 19 IG: 15</p>	<p>1. Attitude: IG more positive attitudes (mean= 4.02, SEM=.06) than CG (mean= 3.85, SEM=.07) (F= 10.05, p&lt;.01). 2. IG expressed fewer concerns about care-of-the-dying than CG 3. Knowledge: IG post-test knowledge scores were statistically significantly higher (mean= 14.17, SEM=.47) than CG (mean= 12.29, SEM=.53)</p>	<p>1. Small number of students 2. Selection bias as self-selected 3. Unknown effect on behaviour 4. IG education theory content and length of time is not standardised. 5. Validity and reliability of outcome measures are not discussed 6. AACEL (Bradley et al 2000) may not be valid for this sample</p>
<p><b>5. Kwekkeboom et al (2006) USA</b> Evaluate the impact of the Palliative Care Companion programme on students' knowledge and attitudes about palliative care and concerns about caring for dying patients</p>	<p>Quasi Experimental IG: O<sub>1</sub> X O<sub>2</sub> CG: O<sub>3</sub> O<sub>4</sub> Pre-test-post-test (4 months) Intervention: orientation, attend seminars and talked with the dying in a hospice (15 weeks) Outcome measure: PCQN; AACEL; CACDP</p>	<p>Total= 52 Baccalaureate, year not given IG: 32 (Female=32, Male=0) CG: 20 (Female=19, Male=1)</p>	<p>1. Attitude: IG &amp; CG had reduced concerns caring for the dying 2. IG significant decrease in concerns about caring for dying patients between pre-test (mean= 9.94, SD= 5.14) and post-test (mean= 7.72, SD= 4.81) t(31)= 2.79, p&lt;0.01 3. Knowledge: IG and CG increased knowledge without statistical significance 4. Behaviour: No significant difference between IG and CG 5. IG self-report journals, more confidence in communication with patients 6. Companion programme described as educational and meaningful</p>	<p>1. Small number of students 2. Less in CG than IG 3. Low reliability AACEL so findings not reported 4. IG and CG reported other forms of learning may influence finding 5. Selection bias as self-selected 6. Unknown effect on behaviour 7. Attrition IG (n=4/36)</p>
<p><b>6. Barrere et al (2008) USA</b> Evaluate the influence of the integration of ELNEC curriculum on a one year and four year baccalaureate nursing programme</p>	<p>Quasi-experimental IG1: O<sub>1</sub> X O<sub>2</sub> IG2: O<sub>3</sub> X O<sub>4</sub> Pre-test-post-test (end of year) Intervention: both groups received ELNEC integrated programme (hours unknown) with a day visit to funeral parlour and hospice Outcome measure: FATCOD</p>	<p>Total= 73 IG1: 39 (Fourth/final year Baccalaureate) IG2: 34 (1year Accelerated Baccalaureate)</p>	<p>1. Attitude: integrated programme positively influenced attitude, statistically significant (t=-5.977, p=.000) 2. Predictors for change were a younger age (18-22 year) and no previous experience. 3. Effect was higher in the four year programme</p>	<p>1. Attrition post-test leading to potential outcome bias (IG1 n=5 11%, IG2 n=9 13%) 2. Length of intervention was unclear. 3. Unknown effect on knowledge 4. Unknown effect on behaviour 5. Varying clinical experience</p>

Table 2.3 Studies evaluating education strategies among pre-registration nurses

Authors/year/country/aim	Methodology/method	Sample	Findings	Limitations
<p><b>7. Dobbins (2011) USA</b> Evaluate the impact of an elective nursing module incorporating the ELNEC curriculum on the attitudes of associate degree nursing students towards caring for the dying</p>	<p>Quasi-experimental Study 1 IG1: O<sub>1</sub> X O<sub>2</sub> CG1: O<sub>3</sub> X O<sub>4</sub> Study 2 IG2: O<sub>5</sub> X O<sub>6</sub> CG2: O<sub>7</sub> X O<sub>8</sub> Study 1 &amp; 2 Pre-test-post-test at end (week 14) Intervention: IG1 IG2, module, theory, film, day visit to funeral parlour and hospice (14 weeks) CG1: Lecture (3 hours) CG2: Lecture &amp; film Outcome measure: DAP-R; FATCOD</p>	<p>Associate degree year unknown Study 1 IG: 12 CG: 25  Study 2 IG:16 CG: 22</p>	<p>1. Attitude: Statistically significant increase in positive attitudes FATCOD IG study 1 <math>t(11) = 3.082, p = .010</math> IG study 2 <math>t(15) = 5.267, p = .000</math> 2. Statistically significant decrease in fear of death Study 1 <math>t(11) = -3.233, p = .008</math> Study 2 <math>t(21) = -2.309, p = .031</math> 3. Study 1 statistically significant difference between IG and CG Study 2 there was no statistically significant difference between the IG &amp; CG, suggesting learning from film and lectures</p>	<p>1. Unknown effect on knowledge 2. Unknown effect on behaviour 3. Some students may have more opportunity for experiential learning than others 4. Unknown if change in attitude was retained</p>
<p><b>8. Weissman (2011) USA</b> The effect of the ELNEC communication module on first-year nursing students</p>	<p>Quasi experimental CG: O<sub>1</sub> X O<sub>2</sub> IG: O<sub>3</sub> X O<sub>4</sub> Pre-test-post-test 3 weeks Intervention: 2.5 hour ELNEC communication module with theory, film discussion &amp; practice active listening CG and IG compulsory ELNEC lecture (hours unknown) Outcome measure: FATCOD; VAS Self-Efficacy Communication</p>	<p>Total= 17 Associate degree, first year IG: 9 (Female=7, Male=2) CG: 8 (Female=7, Male=1) CG &amp; IG from different faculties</p>	<p>1. Attitude: CG pre and post-tests scores similar. CG 0.63 (SD=7.27), IG 6.00 points higher (SD= 7.01) suggesting a greater comfort with death and dying 2. Self-efficacy: IG and CG scores improved. No statistically significant differences between IG &amp; CG</p>	<p>1. Small sample 2. May not be generalizable 3. Unknown effect on behaviour 4. Unknown effect in knowledge 5. Reliability of VAS self-efficacy not established</p>
<p><b>9. Fluharty et al (2012) USA</b> Evaluate the impact of simulation on student knowledge, self-confidence and communication skills. when caring for the dying</p>	<p>Quasi experimental IG: O<sub>1</sub> X O<sub>2</sub> Pre and post-test (immediately after) Intervention: ELNEC lecture (length unknown), simulation prioritise care, role play communication, debrief. Outcome measure: KREOLC; Self-Confidence Caring for the Dying; End-of-Life Communication; Satisfaction with Instruction</p>	<p>Total=329 four faculties. Undertaking medical-surgical course. Year unknown Associate degree: 81 Baccalaureate: 202 Accelerated Baccalaureate: 37 (Female=304, Male=29, Unknown=1)</p>	<p>1. Knowledge: statistically significant increase post-test <math>t(329) = 15.79, p = .000</math> 2. Self-confidence: increase in self-belief (mean 6.86, SD=0.61) 3. Communication: self-reported high (mean 4.33, SD=0.56) suggesting a belief in learning 4. Satisfaction with simulation</p>	<p>1. Content of lectures and simulations not described 2. Unknown if applied skills in the clinical area 3. Reliability and validity of tools not established 4. No control group for comparison 5. Post-test attrition 41/329</p>

Table 2.3 Studies evaluating education strategies among pre-registration nurses

Authors/year/country/aim	Methodology/method	Sample	Findings	Limitations
<p><b>10. Moreland et al (2012)</b>  <b>USA</b>                      Evaluate knowledge of end-of-life signs and symptoms and perceived self-efficacy</p>	<p>Quasi-experimental                      IG: O<sub>1</sub> X O<sub>2</sub>                      Pre-test-post-test (next day)                      Intervention: Video                      Simulation knowledge of end-of-life signs and debrief                      Outcome measure: Knowledge Assessment; Self-efficacy</p>	<p>Total=14 from one faculty                      Baccalaureate Junior (year three):11                      Accelerated Baccalaureate: 3                      (Female=13, Male=1)</p>	<p>1. Knowledge: statistically significant improvement, 74% (mean=5.21) to 85% (mean=6.0) p=.003                      Average of 11%                      2. Self-efficacy: statistically significant improvement in recognising the signs of imminent death.                      35.36-37.79 (p=.05)                      3. Increase in confidence to care for a dying patient                      4. Debrief: Understand the importance of palliative care</p>	<p>1. Small sample so may not be generalizable                      2. No control group for comparison of learning                      3. Reliability of tools not established                      4. Students may have fear of dolls (pediophobia) or humanoid figures (automatonophobia)</p>
<p><b>11. Twigg &amp; Lynn (2012)</b>  <b>USA</b>                      Evaluate the effectiveness of simulation on knowledge and emotional readiness in providing end-of-life care</p>	<p>Quasi experiment                      IG: O<sub>1</sub> X O<sub>2</sub>                      pre-test-post-test (1 week later)                      Intervention: EOLC lecture before simulation, simulation, debrief                      Outcome measure: Knowledge Assessment; Concerns About Dying Scale</p>	<p>Total= 16 Baccalaureate Fourth year/senior                      (Female=13, Male=3)</p>	<p>1. Males reported less stress and anxiety than females before the intervention                      Females before (t=-2.906, p=.012)                      Females after (t=-2.558, p.023)                      2. Knowledge: significant improvement (t=0.775, p=.451)                      3. Students reported higher level of stress and anxiety after the simulation (t=-2.402, p=.031)                      This may be due to the first exploration into care-of-the-dying. May be aware of the care needs when qualify in 6 months                      4. No difference between those with previous professional or personal experiences with EOLC (p&lt;.05)                      5. Pleased to have this opportunity                      6. Requested simulation to be in curriculum</p>	<p>1. Small convenience sample so may not be generalizable                      2. No control group for comparison                      3. Students may have fear of dolls (pediophobia) or humanoid figures (automatonophobia)                      4. Lecture content and length is unknown</p>

Key:  
 CG = Control Group; IG = Intervention Group; O = Observation; X = Intervention (Campbell & Stanley 1963);  
 AACEL= Attitudes About Care at the End of Life (Bradley et al 2000); CACDP= Concerns About Caring for Dying Patients (Milton 1984); Collette-Lester Fear of Death Scale (Collett-Lester 1969);  
 DAP-R Death Attitude Profile Revised (Wong et al 1994); EOLC= End of Life Care; End-of-Life Concerns About Dying Scale (Mazor et al 2004); Communication (Fluharty et al 2012); ELNEC= End-of-Life Nursing Education Curriculum (AACN 2000); EOL= End-of-Life; F= F test; FATCOD = Frommelt Attitude Toward Care-of-the-Dying (Frommelt 1991); Knowledge Assessment (Moreland et al 2012); Knowledge Assessment (Twigg & Lynn 2012); KREOLC = Knowledge Related to End-of-Life-Care (Fluharty et al 2012); p= p value; PCQN= Palliative Care Quiz for Nurses (Ross et al 1996); Satisfaction with Instruction (Fluharty et al 2012); SD= Standard deviation; Self-Confidence Caring for a Dying Patient (Fluharty et al 2012); Self-Efficacy (Moreland et al 2012); t= t test; VAS= Self-Efficacy Communication (Weissman 2011); WfQUDPF= Winget Questionnaire for Understanding the Dying Person and his Family (Ward & Lindeman 1978)



Table 2.4 ReLIANT: appraisal framework (Koufogiannakis et al 2006)  
Numbers refer to studies Tables 2.3

Screening questions	Yes	No	Unclear
<b>1. Is the objective of the study clearly stated?</b>	1,2,3,4,5,6,7,8,9,10,11		
<b>2. Is the population described in detail?</b> Is the number of participants clearly stated? Description of age, gender, previous experience? Are participants required to participant?	1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11 2,6,9	1,3,4,5,7,8,10,11	
<b>3. Are groups of participants that are receiving different education interventions similar in their size and population?</b> Other than the intervention are groups treated equally?	1,3,4,5,6,8 1,2,3,4,5,6,7,8,9,10,11	2,7,9,10,11	
<b>4. What research method used?</b> Is the methodology clearly stated? Is it appropriate for the question/ aim? Attempt to avoid bias via randomising? The method of allocation was described?	1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11 1,3 1,3,4,5,7,8	2,4,5,6,7,8,9,10,11 2,6,9,10,11	
<b>5 When are learning outcomes measured post-test?</b> Immediate Short term Long term	1,2,3,9,10 3,4,5,6,7,8,11 1	4,5,6,7,8,11 1,2,9,10 2,3,4,5,6,7,8,9,10,11	
<b>6. Is the research instrument described? Is the instrument validated?</b>	1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,11	8,9,10,11	
<b>7. Educational context</b> The type of learning environment (university)? Mode of teaching method (lecture, video, simulation) Outlines philosophy/ theoretical basis of the instruction? Is the instructional topic clearly described? Are learning objectives stated? How much instructional contact time was involved? Cognitive (knowledge) outcomes Affective (attitude) outcomes Behavioural outcomes	1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11 2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11 8,9 1,2,3,4,5,7,8,9,10, 2,3,5,9,10,11 1,3,4,5,6,7,8,11 1,8,9,10	1,2,3,4,5,6,7,10,11 6,11 1,4,6,7,8 2,9,10 2,3,4,5,6,7,11	1
<b>8.Results</b> Are the results of the study clearly explained? Do the results address the original research question? Was the reported outcome positive or negative? Does the reported data support the conclusions? Potential problems with the research design presented?	1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11 12,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11		
<b>9. Did the study have enough participants to minimise the play of chance?</b> Power calculation	1	2,3,4,5,6,7,8,9,10,11	
<b>10. How are the results presented?</b> Results are presented as a proportion – mean/ median How precise was the estimate of the treatment effect? confidence interval p-value	1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,9,10,11	1,2,3,4,5,6,7,9,10,11 8	
<b>10. Relevance. Can the results be applied?</b> The study population are similar to my learners? Learning needs the same as my learners? Practice implications of this research reported? Results of this study directly transfer to my practice?	1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11 1,2,3,4,5,6,7,8,9,10,11	1,2,3,4,5,6,7,8,9,10,11	

group was not available (Arber 2001, Barrere et al 2008, Dobbins 2011, Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). Overall, selection bias was judged to be low. Internal validity was achieved by selecting appropriate methodology and data collection methods. Also the findings were relevant to exploring the effectiveness of EOLC educational initiatives for P-RNs.

### Sample size

Sample size varied between 14 (Moreland et al 2012) and 370 (Fluharty et al 2012). Only Degner and Gow's (1988) study performed a power calculation to determine the minimum sample size required to have a high chance of detecting real between group differences (Greenhalgh 2010). Some studies achieved larger samples by recruiting from more than one Faculty (Degner & Gow 1988, Fluharty et al 2012), whilst studies that recruited in a single HEI tended to have smaller samples (Weissman 2011, Moreland et al 2012, Twigg and Lynn 2012). Statistically significant differences were reported in many studies, however, without a power calculation these findings may be underpowered (Arber 2001, Mallory 2003, Kwekkeboom et al 2005, 2006, Barrere et al 2008, Dobbins 2011, Weissman 2011, Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). Kwekkeboom et al (2005, 2006) and Dobbins (2011) repeated their studies and found similar results which strengthens the validity of the findings.

The samples comprised undergraduate P-RNs from four programmes (Table 2.3). Some were in the first and second years of associate degree programmes, (Dobbins 2011, Weissman 2011, Fluharty et al 2012). Others, from four-year baccalaureate programmes, included third year (junior) and final year (senior) students (Degner & Gow 1988, Mallory 2003, Kwekkeboom et al 2005, 2006, Barrere et al 2008, Moreland et al 2012, Fluharty et al 2012, Twigg & Lynn 2012). Two studies included participants from one year accelerated baccalaureate programmes (Barrere et al 2008, Moreland et al 2012) and finally one study included third (final) year P-RNs undertaking an undergraduate degree in UK (Arber 2001).

### Educational interventions and locations

Education in EOLC was delivered using a variety of methods. Theory was delivered as a lecture combined with cinemeducation (Kwekkeboom et al 2005,

2006, Dobbins 2011, Weissman 2011), experiential learning (Degner & Gow 1988, Arber 2001, Mallory 2003, Kwekkeboom et al 2005, 2006, Barrere et al 2008, Dobbins 2011) or simulation (Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012) (Table 2.3).

The education content also varied. One study in Canada of third year baccalaureate nurses in two faculties compared a module of EOLC education with integration throughout the programme. It is not clear, however, if the content followed standardised guidelines for education in EOLC (Degner & Gow 1988). In England a module for final year degree P-RNs was guided by the European Oncological Nursing Society recommendations for P-RNs (EONS 1994, Arber 2001). Nine studies in the USA evaluated the End-of-Life Nursing Education Consortium Curriculum (ELNEC) (Mallory 2003, Kwekkeboom et al 2005, 2006, Barrere et al 2008, Dobbins 2011, Weissman 2011, Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). ELNEC commenced in 2000 to improve EOLC education of undergraduate nurses undertaking either a two year Associate Degree, four year Baccalaureate or one year Accelerated Baccalaureate (AACN 2000, 2004a, 2014). The competencies and teaching aids were devised by palliative care experts and delivered by ELNEC trained lecturers during lectures, case discussions, video/films, role play and simulation as either a distinct module or integrated throughout a programme (AACN 2004a, Dickinson 2007). It comprised EOLC, pain and symptom management, communication, loss grief and bereavement (AACN 2007). However it is unclear how much time is allocated to each of these topics in each study.

The amount of clinical experiential learning in a hospice/cancer unit varied between one day (Mallory 2003, Dobbins 2011), five days (Arber 2001), one day a week for two semesters (Degner & Gow 1988) and volunteering as a companion for 15 weeks (Kwekkeboom et al 2005, 2006). Barrere et al (2008) also describe a placement in a hospice and hospital but the length of time is unspecified. It is unknown if the amount of time in the CLE impacted on P-RNs learning as a longer placement may have provided more opportunity to observe EOLC and sensitive communication.

### Outcome measures

Participants in each study completed outcome measures at the beginning and end of the study period. These measured attitudes, fear of own death/dying and

concerns about caring for patients and relatives (Table 2.5). Knowledge outcomes measured symptoms assessment/management and grief (Table 2.6). Finally behavioural outcomes measured self-efficacy in communications, managing own emotions and assessing a patient (Table 2.7).

Table 2.5 Outcome measures for attitude

Author/year/ tool/ (studies)	Fear of death emotional impact on self	Concerns about delivering care	Concerns about communication	Personal experience of death	Demographic
Bradley (2000) Attitude About Care at the End-of-Life (AACEL) (Kwekkeboom et al 2005, 2006)		Responsibility Prescribing Hospice	Clinician-patient communication Hospice referral		
Collett-Lester (1969) Collett-Lester Fear of Death Scale (Degner & Gow 1988)	Death/dying of self Others death/dying				
Frommelt (1991) Frommelt Attitude Towards Care of the Dying-FATCOD (Mallory 2003, Barrere et al 2008, Dobbins 2011, Weissman 2011)	Emotional impact on self	Symptom control	Communication with patients and relatives		Age Qualification Education and experience in death/dying
Milton (1984) Concerns about Caring for Dying Patients. (Kwekkeboom et al 2005, 2006)	Psychological effects on self	Physical care Post-mortem	Emotional support patients/families	Death of own family members	
Mazor et al (2004) Concerns about Dying (Twigg & Lynn 2012)	Fear of own death Emotional impact on self				
Winget Questionnaire for Understanding the Dying Person and his Family (Ward & Lindeman 1978) (Degner & Gow 1988)	Dying patients and their family			Death among own family members Talking to the dying	Gender Age Religion Profession
Wong et al (1994) Death Attitude Profile Revised DAP-R (Dobbins 2011)	Fear of death Death avoidance/ acceptance				

Table 2.6 Outcome measures for knowledge

Author/year/ tool/(studies)	Assessing symptoms	Symptom management	Family grief	Nurses emotional response/ burn out
Fluharty et al (2012) Knowledge Related to End-of-life Care (Fluharty et al 2012)	Assessing symptoms	Symptom management		
Moreland et al (2012) Knowledge Assessment Instrument (Moreland et al 2012)	Recognise imminent death			
Ross et al (1996) Palliative Care Questionnaire for Nurses (PCQN) (Arber 2001, Kwekkeboom et al 2005, 2006)	Assessing symptoms	Symptom management	Family grief	Nurses emotional response/burnout
Twigg & Lynn (2012) Knowledge in End-of-Life Care (Twigg & Lynn 2012)		Symptom management		

Table 2.7 Outcome measures for behaviour

Author/year/ tool/(studies)	Communication	Emotional response	Assess patient	Documentation
Fluharty et al (2012) Self-Confidence in Caring for a Dying Patient (Fluharty et al 2012)	Communication		Assess patient	
Fluharty et al (2012) End-of-Life Communication Assessment tool (Fluharty et al 2012)	Communication			
Moreland et al (2012) Self-Efficacy Assessment Instrument (Moreland et al 2012)		Emotional response	Assess patient	Documentation
Weissman (2011) Visual Analogue Scale Self-Efficacy Communication with a Dying Patient (Weissman 2011)	Communication			

Validity and reliability of the 16 outcome measures used were variable (Appendix 2). The least valid and reliable was Attitudes About Care at the End-of-Life (AACEL) (Bradley et al. 2000) used by Kwekkeboom et al (2005, 2006). It was tested for validity and reliability to assess RNs' and doctors' attitudes and prescribing, which may not be applicable for P-RNs. Kwekkeboom et al (2006) reported that AACEL lacked internal consistency (Cronbach's alpha <0.38) and therefore did not report the findings from the second study. This suggests findings from the AACEL reported by Kwekkeboom et al (2005) should be viewed with caution. The remaining measures report Cronbach alpha >.7 which Hinton et al (2014) considers to show high reliability (Winget 1978, Denger & Gow 1988, Frommelt 1991, Wong et al 1994, Mazor 2004, Fluharty 2012). Cronbach alpha was not reported for the Knowledge Related to End-of-life Care (Fluharty et al 2012), Knowledge Assessment Instrument (Moreland et al 2012), Self-Efficacy Visual Analogue Scale (Weissman 2011) and Knowledge in End-of-Life-Care (Twigg & Lynn 2012).

## Findings

The educational strategies used in the studies include theory, experiential learning, cinemeducation and role play/simulation. The results are therefore presented according to the outcome measures of attitude, behaviour, knowledge, age/previous experience and the programme.

### Attitudes towards end-of-life-care

Attitude to EOLC was assessed on the basis of a P-RN's personal fear of death/dying, as well as concerns about communicating and caring for patients and relatives (Table 2.5). Attitudes towards the dying improved and fear of

death reduced when EOLC theory was combined with experiential learning (Degner & Gow 1988, Mallory 2003, Kwekkeboom et al 2005, 2006, Barrere et al 2008, Dobbins 2011). Attitudes also improved following lectures about communication combined with role playing (Weissman 2011). Conversely, stress increased following simulation (Twigg & Lynn 2012). The strength of these studies is the positive effect education has on P-RNs' attitudes towards the dying (Table 2.3).

Positive attitude may be influenced by the amount of clinical experience and theory in EOLC. In one study this consisted of one day a week for two semesters in a hospice/cancer ward combined with 72 hours of theory (Degner & Gow 1988), while the Companion Programme volunteers visited people who were dying in a hospice for 15 weeks, although the number of hours of attendance is unknown (Kwekkeboom 2005, 2006). This was combined with the compulsory ELNEC curriculum and optional extra seminars, reading and cinemeducation (Kwekkeboom 2005, 2006). In contrast the control group received 6 hours of theory but no experience in the hospice setting (Degner & Gow 1988) or the compulsory ELNEC curriculum (Kwekkeboom 2005, 2006). Following these strategies there were fewer concerns and a more positive attitude towards EOLC in the intervention groups (Degner & Gow 1988, Kwekkeboom 2005, 2006) (Table 2.3). This suggests that learning EOLC is enhanced when theory is combined with a hospice/cancer placement. Kwekkeboom (2006) found the pre-test scores for concerns about EOLC were low for both the companions and the control group. This may be due to both groups attending compulsory ELNEC modules and providing EOLC in other clinical placements.

Experiential learning was much shorter in some studies with a day visiting a hospice and mortuary combined with ELNEC modules (Mallory 2003, Barrere et al 2008, Dobbins 2011) (Table 2.3). Mallory (2003) found P-RNs' attitudes were more positive in those who received the ELNEC modules and day visits, compared to those in the control group. Although this is only one study, it appears that theory with experiential learning is more effective than no education. Barrere et al (2008) found a statistically significant improvement in attitude towards care of the dying in response to ELNEC education irrespective of whether P-RNs were undertaking a one year accelerated or four year

baccalaureate programme. In addition it has been suggested that P-RNs' attitudes mature as they provide EOLC in the clinical environment which may influence the findings (Degner & Gow 1988, Barrere et al 2008).

Cinemeducation involves watching a film and reflecting upon the characters' experiences. Dobbins (2011) evaluated cinemeducation as part of a 14 week ELNEC module in two studies (Table 2.3). In Study 1 the intervention group undertook the 14 week ELNEC module and watched the film *Wit*. The control group received a three hour lecture on EOLC and did not watch the film. There was a statistically significant increase in attitude and a statistically significant decrease in fear of death among the intervention group compared to the control group. In Study 2, the intervention group attended the 14 week ELNEC module and the control group received a three hour lecture and both groups watched the same film. Whilst attitude improved and death anxiety decreased in both the intervention and control group this was not statistically significant (Dobbins 2011). It is difficult to identify factors that contributed towards a change in attitude but it is possible the addition of cinemeducation enhanced learning. This could result from reflecting on patients and relatives' experiences and their own emotions which may not be possible in the clinical setting.

Two studies reported improvements in attitude can last for a significant amount of time. Mallory (2003) found an improved attitude was remained four weeks later. However, it is unknown how this affected P-RNs' interactions with patients and relatives. Nevertheless these findings suggest that increasing understanding regarding EOLC may improve attitudes towards the dying. In an important study by Degner & Gow (1988) participants undertook a second post-test a year after registration as a nurse. Death anxiety decreased over time and attitude improved suggesting a maturation effect as individuals gained experience in EOLC (Degner & Gow 1988). Findings from the control group who received six hours of theory without hospice experience also experienced increased positive attitudes towards the dying and decreased death anxiety. However, their second post-test scores were similar to those of the intervention group at first post-test assessment. This suggests that without EOLC education the control group took longer to develop positive attitudes.

Weissman (2011) compared students who attended ELNEC lectures (CG) against students who received an ELNEC lecture, lecture about barriers to

communication, cinemeducation and practicing attentive listening (2.5 hours) (IG) (Table 2.3). Whereas there was a small improvement in attitude in the control group, scores were higher for the intervention group suggesting a greater ease with death and dying as a result of having the opportunity to practice communication skills. Twigg and Lynn (2012) incorporated EOLC lectures, cinemeducation, role playing and patient assessment using a high fidelity mannequin and communicating with angry relatives. They found no difference in P-RNs' pre-test-post-test scores related to previous personal or professional experiences with the dying. P-RNs reported greater stress and anxiety after the simulation. This may be due to their inexperience responding to angry relatives and the realisation of how their role will change when they become RNs. Although this was stressful, students were pleased to have this opportunity to explore their responses before registration and learning appeared to have occurred.

### Knowledge

Studies explored P-RNs knowledge about symptom assessment and management (Table 2.3, 2.6). Three studies that combined experiential learning with theoretical strategies reported improvement in knowledge using the Palliative Care Quiz (Ross et al 1996). Arber (2001) evaluated an optional module that combined 50 hours theory with 5 days in a hospice. Kwekkeboom et al (2005) also reported a statistically significant increase in knowledge following the Companion Programme. A second study by Kwekkeboom et al (2006) found a non-statistically significant improvement in both the intervention and control group's knowledge. This could be due not only to both groups learning from the compulsory ELNEC modules but also control group members had each taken care of at least four people who were dying, hence providing an opportunity to learn symptom control. The exact number of hours the intervention group spent with patients was not recorded, therefore, it is unclear which learning activities improve knowledge, but it appears to be a combination of both theory and clinical learning.

Studies into simulation also reported a statistically significant increase in knowledge about symptom management and signs of imminent death among third year (junior) students (Fluharty et al 2012, Moreland et al 2012). In contrast, Twigg & Lynn (2012) reported fourth year (senior) students, due to



qualify in six months, had an increase in knowledge, which was not statistically significant. This may have been influenced by the small sample (n=16).

Differences between junior and senior students' change in knowledge may be due to senior students having completed EOLC modules and experiential learning. Learning through simulation may be more meaningful than theory due to the interactive scenario with changing vital signs and relatives' questions. Importantly the debrief following each scenario, provided an opportunity to reflect on the rationale for the differing decisions and responses that may not be possible in the CLE (Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012).

### Behaviour

Participants reported their self-perceived ability to care and communicate with the dying and their relatives in several studies (Degner & Gow 1988, Kwekkeboom et al 2006, Weissman 2011, Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012) (Table 2.3, 2.7). Students in two studies reported their actual behaviour with patients and relatives. The diary entries of the P-RNs' who were companions described these interactions as rewarding, and helping to develop their communication skills (Kwekkeboom et al 2006). Degner and Gow (1988) interviewed P-RNs who attended a module and worked one day a week in a hospice. They described feeling prepared to provide EOLC. In the second post-test, as RNs they were more likely to discuss with patients their preferred place to die, make referrals and inform the family of changes, compared to the control group (Degner & Gow 1988). Although how P-RNs learn in the CLE was unclear, the combination of theory with the opportunity to observe expert role models' interactions with patients and relatives may have provided a model to imitate in their own clinical practice (Degner & Gow 1988, Kwekkeboom et al 2006, Barrere et al 2008).

Three studies explored self-efficacy following communication training (Table 2.3). Weissman (2011) found both the control group who did not receive communication training, and the intervention group, reported greater confidence in EOLC. There was no significant difference between the groups, which, Weissman (2011) suggest may be influenced by role play providing a more realistic challenging conversation which dented students' confidence. In contrast, self-efficacy in communication following simulation was high (Fluharty

et al 2012) and statistically significantly higher than pre-test (Moreland, et al 2012). However, the retention and application of communication skills in the CLE were not explored (Moreland et al 2012, Fluharty et al 2012). Behaviour and self-efficacy were also not explored in the remaining studies (Arber 2001, Mallory 2003, Kwekkeboom et al 2005, Barrere et al 2008, Dobbins 2011, Twigg & Lynn 2012).

#### Influence of age, gender and previous experience

Mallory (2003) and Twigg and Lynn (2012) found prior EOLC experience did not have an effect on students attitudes towards EOLC. Barrere et al (2008) found that gender, previous degrees and education were not a significant predictor of a change in attitude. However, younger students (18-22 years) and those without personal or professional experience of EOLC were more likely to develop positive attitudes (Barrere et al 2008) (Table 2.3). This may reflect their lack of prior experience and knowledge. Conversely, it may be that older students' previous personal experiences, contributed to their learning EOLC. This warrants further investigation. Other studies did not explore the influence of age and personal experiences on learning. Therefore, it is not possible to form strong conclusions regarding the influence of age, gender or experience upon attitudes towards the dying.

#### Stage of programme

Educational strategies were undertaken at differing stages of the programme (Table 2.3). Some were towards the beginning with junior students (Mallory 2003, Fluharty et al 2012, Moreland et al 2012), while others were in the final year (Degner & Gow 1988, Arber 2001, Twigg & Lynn 2012). Placing EOLC at the beginning of a curriculum may be challenging as students may have little background clinical practice to draw on. Alternatively this may help prevent P-RNs from developing false ideas and assumptions and create positive coping strategies (Mallory 2003). In contrast, educational initiatives towards the end of a programme may leave little time to practice the skills in the CLE and leave P-RNs vulnerable in the CLE as they have neither knowledge nor skills to provide EOLC.

A third option is to integrate EOLC theory throughout the programme with content distributed at different stages (AACN 2004b). Weismann (2011) recommends communication training should begin early and be developed over

the course of the programme to help the student gain a deeper understanding of theory and implement strategies. These findings suggest that P-RNs' knowledge, attitudes and self-reported behaviour are enhanced following a variety of methods of learning during both optional modules and integrated content. Some studies reported a statistically significant difference, with discrete modules resulting in more positive attitudes compared to an integrated programme (Degner & Gow 1988, Dobbins 2011, Weisman 2011). A full semester module allows a systematic coverage of EOLC as an established component of undergraduate nursing modules (Arber 2001, Mallory 2003). In contrast, when threaded throughout the curriculum, P-RNs learn EOLC simultaneously with resuscitation, as well as chronic and life threatening diseases, to provide holistic care in a wide selection of scenarios (Barrere et al 2008).

In summary, P-RNs appear to develop knowledge, and positive attitudes towards the dying through experiential learning combined with theory. Simulation and cinemeducation may provide opportunities to reflect on patients' and relatives' experiences and practice communication skills. However, these strategies warrant further investigation, as they do not explore how individuals learn in the CLE.

## **Discussion**

The findings from these studies suggest a positive change in attitude and knowledge may occur following theory, cinemeducation, simulation and experiential learning. It has been suggested that nursing education focuses on learning the skills and knowledge to perform tasks and that little attention has been given to developing nurses' attitudes (McQueen 2004). A strength of the reviewed studies is the focus on developing positive attitudes towards EOLC. Learning appears to be enhanced when P-RNs have the theory of EOLC with a role model and supervised clinical practice (Degner & Gow 1988, Mallory 2003). Indeed social learning theory suggests learning alongside a clinical expert enhances learning (Bandura 1986). However, the other studies did not explore the influence of learning EOLC alongside a RN who is a mentor in the clinical learning environment (Arber 2001, Kwekkeboom et al 2005, 2006, Barrere et al 2008, Weissman 2011, Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). It has been reported that the opportunity to observe

experts and receive positive feedback may encourage P-RN's self-confidence and the repetition of desired behaviour (Levett-Jones & Lathlean 2008, Bradbury-Jones et al 2010a). However none of these studies explored P-RNs' experiences of learning EOLC in the CLE and further research is required.

Simulation has been recommended as a method of experiential learning to address these issues (NMC 2007). Berragan (2014) has suggested that simulation may place the student at the centre of learning. In addition, one of the challenges for P-RNs is to bundle together complex activities (Spouse 2001a). EOLC simulation scenarios appear to afford the opportunity to combine recognising changes in a patient's condition, with prioritising care, and communication (Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). This may link theory to practice in a more meaningful way than lectures alone (Kopp & Hanson 2012, Twigg & Lynn 2012). Facilitated debrief may also promote deeper learning through critical thinking and problem solving (Bengtsson & Ohlsson 2010, Bland et al 2011). This is supported by studies in which students report EOLC simulation prepares them to recognise the cues of distress and listen to the family (Leighton & Dubas 2009, Gillan et al 2013a).

Miller & Bull (2013) suggests that simulation is a safe learning environment compared to the CLE. Yet EOLC simulation may cause flashbacks to previous professional or personal experiences of peaceful and traumatic deaths (Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). Although anxiety decreased following the scenarios of peaceful death during simulation (Fluharty et al 2012, Moreland et al 2012), it increased following a scenario around communication with a family in conflict and denial (Twigg & Lynn 2012). It could be argued that creating some anxiety may replicate an authentic environment which may be beneficial when coupled with exploring techniques to manage emotions (Foronda et al 2014). Indeed, students have consistently evaluated debrief as an important strategy to explore taboos about death and techniques to manage the emotional impact (Smith-Stoner 2009, Leighton & Dubas 2009, Hamilton 2010, Kopp & Hanson 2012, Ladd et al 2013). This suggests that simulation in EOLC requires a facilitator skilled in guiding the management of emotions.

There is evidence that the process of simulation itself can be stressful, as P-RNs are singled out or feel stupid, which may inhibit learning (Laster 2007).

Lecturers have reported fear of mannequins (pediophobia, automantonophobia) or hesitancy when initially faced with mannequins that moan or talk (Moreland et al 2012, Smith-Stoner 2009). Hence, it is important that lecturers do not become focused on the technology, but create a positive learning environment with gentle encouragement.

Simulation cannot replace real life experiences as skin changes and chest rattle are not present in all mannequins (Gillan et al 2013b). In addition, role playing even with scripts cannot replicate the variable responses in the real CLE, although actors may increase authenticity (Leigh 2008, Pike & O'Donnell 2010). Thus students need to understand the differences to ensure effective learning (Bland et al 2014). Despite these limitations there is a body of evidence that suggests simulation in EOLC with a mannequin based scenario and debrief might provide an opportunity to develop knowledge and communication skills.

Cinemeducation aims to engage the students and explore their own intellectual and emotional reactions in situations resembling real life (Alexander & Wasman 2000). Films have been used for teaching psychology and counselling (Zauderer & Ganzer 2011). In the nursing literature whilst there have been descriptions of the techniques there is a dearth of research. Parker and Faulkes (2004) used the film 'My Life,' about a cancer diagnosis, with stimulating questions to provoke deep thinking, emotional healing and holistic care during a reflection activity with 28 RNs. Carpenter et al (2008) found a character receiving chemotherapy in the film 'Wit' helped to clarify students' own attitudes and the values of nursing. An innovative written assignment was created by Di Bartolo & Seldromridge (2009), in which, students watched 'Tuesday with Morrie' or 'Whose Life is it Anyway?' then answered questions. This appeared to enhance self-awareness and engage students in thinking about the importance of quality of life and end-of-life issues (Di Bartolo & Seldromridge 2009). Cinemeducation seems to be especially helpful in allowing students the opportunity to explore a situation they may not experience in the CLE.

In summary, learning occurs in the HEI and CLE. While, cinemeducation and simulation have the potential to enhance experiential learning by providing an opportunity to witness communication and reflect on patients and relatives experiences, they warrant further investigation in England.

## **Limitations of the studies and review**

Undergraduate nurses' education in EOLC is an important issue. Although the search strategy identified 11 studies, this did not include non-published studies or non-English language publications, so may have excluded some relevant citations. Ten studies were conducted in the USA or Canada, and therefore, it is unclear if these findings can be transferred to the UK due to the differing nursing education and care delivery systems. Whilst the studies were generally considered methodologically rigorous when judged against the criteria in the ReLIANT appraisal tool, there were two common limitations. Some participants were volunteers from compulsory end-of-life modules (Degner & Gow 1988, Mallory 2003, Barrere et al 2008, Fluharty et al 2012), whilst others self-selected into optional educational activities (Arber 2001, Kwekkeboom et al 2005, 2006, Dobbins 2011, Moreland et al 2012, Twigg & Lynn 2012). This could create a degree of selection bias as participants who volunteered may have a specific interest in EOLC.

Furthermore, a study must be continued for long enough for the effect of the educational intervention to be reflected in the outcome variable. Conversely, attrition may be higher the longer the time between interventions and post-test (Cohen et al 2011). Attrition was not reported for some studies (Kwekkeboom 2005, Dobbins 2011, Weissman 2011, Moreland et al 2012, Twigg & Lynn 2012). However, most studies experienced post-test attrition so that analysis was conducted only on those who completed both the pre and post-tests (Degner & Gow 1988, Arber 2001, Mallory 2003, Kwekkeboom 2006, Barrere et al 2008, Fluharty et al 2012). Thus inflating the chance of finding a difference between pre and post-test as those who did not complete the second assessment may be less likely to have positive outcome. It might be suggested that although a post-test on the same day as the intervention may reduce attrition, it is unknown if the knowledge is retained over time (Fluharty 2012). Nevertheless these studies contributed important evidence in this field.

## **Summary**

The reviewed studies seemed to show that the educational strategies cinemeducation, simulation, theory and experiential learning lead to a positive change in attitude and knowledge in learning EOLC. This was assessed using questionnaires developed by nurse educators so that arguably these did not

include the P-RNs perspective which may be different and illuminate why these strategies enhanced learning. The reviewed studies measured changes in attitude, knowledge and behaviour, but there is a lack of qualitative studies that explore P-RNs' opinions of learning EOLC. The paucity of research in England highlights the need for more studies of undergraduate EOLC education. Finally participants reported attitude, knowledge and self-report behaviour scores were higher among those with experiential learning combined with theory. This suggests that P-RNs may learn from observing RNs in the CLE. However their clinical experiences are not explored in these studies. Therefore, the following chapter will explore P-RNs' experiences providing EOLC by a synthesis of qualitative research.

## **Chapter 3 Pre-registration nurses' experiences providing end-of-life-care: A meta-synthesis**

### **Introduction**

The previous chapter explored the effectiveness of education in EOLC on P-RNs' attitude, knowledge and behaviour. This chapter presents a meta-synthesis undertaken to explore P-RNs experiences of EOLC. There are two benefits to undertaking a meta-synthesis, firstly to gain an in-depth understanding of P-RNs' experiences and the factors that influence these. Secondly, to guide the development of the research question and research design. The meta-synthesis is of particular importance as it explores the context of learning EOLC in the CLE. This chapter will define meta-synthesis, its uses and limitations and give the rationale for using meta-ethnography. The substantive part of the chapter is a meta-ethnography of P-RNs' experiences of EOLC.

### **Defining meta-synthesis**

To understand the advantages of undertaking a synthesis of qualitative studies, it is necessary to define the terminology. Synthesis has been defined as:

‘an activity in which separate parts are brought together to form a ‘whole’ ... with some degree of innovation so that the result is greater than the sum of its parts’ (Noblit & Hare 1988 p 16).

Thus something new is created from more than one study report. Meta-synthesis is the overarching term for a variety of methods to synthesise qualitative research findings from a number of studies. The findings interpreted by the researcher, are extracted from each study report, categorised and synthesised into something new (Noyes et al 2011). Five types of synthesis have been identified: grounded formal theory (Glaser & Strauss 1967); meta-study (Paterson et al 2001); meta-narrative (Greenhalgh et al 2005); meta-ethnography (Noblit & Hare 1988) and framework synthesis (Pope et al 2000, Noyes et al 2011) (Table 3.1).

### **The advantages of a meta-synthesis**

There are several advantages to undertaking a meta-synthesis. Firstly it enables the translation of isolated qualitative studies using a systematic process to reveal a greater breadth, depth and insight than individual studies



Table 3.1 Comparison of meta-synthesis (Adapted from Barnett-Page & Thomas 2009)

Type of meta synthesis/ authors	Deductive/ Inductive	Uses study reports with similar or different methodologies	Quality assessment	Going beyond the primary study	Synthesis product
<b>Framework synthesis</b> (Pope et al 2000)	Deductive	Heterogeneous	Ten criteria	Translation (describe and summarise)	Directly informs policy/ practitioners
<b>Grounded formal theory</b> (Glaser & Strauss 1967)	Inductive	Homogeneous	A personal note about the context, quality and usefulness of each study	Transformation (new interpretation)	Requires further interpretation by policy makers and practitioners
<b>Meta-ethnography</b> (Noblit & Hare 1988)	Inductive	Heterogeneous or Homogeneous	No quality assessment (Noblit & Hare 1988) Later studies have used CASP and other tools	Translation (describe and summarise)	Requires further interpretation by policy makers and practitioners
<b>Meta-narrative</b> (Greenhalgh et al 2005)	Inductive	Heterogeneous	Validity of method, conclusions, samples size	Transformation (new interpretation)	Requires further interpretation by policy makers and practitioners
<b>Meta-study</b> (Paterson et al 2001)	Inductive	Heterogeneous	Excluded non qualitative studies all relevant qualitative studies included	Transformation (new interpretation)	Requires further interpretation by policy makers and practitioners

alone can reveal (Finfgeld-Connett 2010). Secondly, literature reviews describe studies and their findings, whereas meta-synthesis undertakes a higher order interpretation to generate a comprehensive theory from multiple studies (Doyle 2003). Thirdly, a descriptive meta-synthesis produces a comprehensive analysis of phenomena while interpretive meta-synthesis provides more insight by seeking to explore reasons, similarities and differences in the findings (Barbour & Barbour 2003). Thus instead of a description of how people feel, an understanding of why they feel and behave emerges (Popay 2005, Noyes et al 2011). Fourthly, a descriptive or interpretive meta-synthesis provides a different perspective that complements a review of quantitative literature by exploring participants' experiences of an intervention (Atkins et al 2008). Finally the findings can be used to inform and define a research question (Noyes et al 2011).

### **Brief critique of meta-synthesis**

When choosing a meta-synthesis method a number of issues need to be considered. There are several debates about whether it is possible to synthesise qualitative data. Qualitative research seeks to explore the individual's unique perspective within the context of their gender, age and situation. Therefore, placing the findings in juxtaposition during meta-synthesis removes the context and loses the individual's voice (Sandelowski 2006, 2007). Conversely, decontextualisation needs to occur for theory explication and makes the findings from several reports accessible to influence practice and policy (Finfgeld 2003). Meta-synthesis is further complicated by rich description and context being limited by the word count in study reports and the differing methods (Atkins et al 2008). Framework synthesis is deductive, recording findings against an a priori list of codes completely removed from context (Pope et al 2000, Finfgeld 2003). In contrast, inductive methods such as meta-ethnography refer to context by using the original language in the findings as a metaphor (Noblit & Hare 1988), while formal grounded theory explores codes that reveal the influence of context (Strauss & Corbin 1998, Finfgeld-Connett 2006), and meta-study includes the social and political context (Paterson et al 2001). Meta-narrative includes the context across the differing disciplines supplying the evidence (Greenhalgh et al 2005), although the reader may need to review the original study reports for a detailed exploration (Finfgeld 2003).

The issue of whether it is possible to use studies with different qualitative methodologies in the same meta-synthesis also requires consideration. Estabrooks et al (1994) and Jensen and Allen (1996), caution that combining results from differing methodologies can yield a misrepresentation of the findings. Kearney (2001) and Eaves (2001) built grounded formal theory from like-as-like grounded substantive theories, which they argue strengthens the findings. Conversely, Finfgeld-Connett (2010) argued that synthesizing data from multiple qualitative methodologies has the potential to be a useful form of triangulation that reveals similar findings from different perspectives as achieved in meta-ethnographies that incorporated grounded theory and phenomenology study reports by Beck (2011), Lipworth et al (2011) and Gomersall et al (2011). This appears to be possible where the original findings are interpreted into themes/categories that can be compared rather than long narrative text (Sandelowski & Barroso 2003).

Authors are divided on the merits of quality assessment and the exclusion of studies based upon design weakness. Different meta-synthesis methods use different approaches to critical appraisal of study reports. Framework synthesis has specific criteria to exclude flawed research (Barnett-Page & Thomas 2009). In formal grounded theory, quality is discussed in terms of context and usefulness of the findings (Barnett-Page & Thomas 2009). Meta-study includes all qualitative studies that inform the theory (Paterson et al 2001). Noblit and Hare's (1988) meta-ethnography emerged before criteria to establish trustworthiness were devised and there is no discussion about quality, but recommends studies are included based upon the usefulness of the findings. Later meta-ethnographers such as Britten et al (2002) and Campbell et al (2003), recommend the appraisal of qualitative reports and exclusion of studies of poor quality to promote trustworthiness and credibility. Eakin and Mykhalovsky (2003) and Barbour and Barbour (2003) warn that influential older qualitative research could be excluded from reviews due to not fulfilling a research critical appraisal protocol, whereas, contemporary study reports, may include a more comprehensive research design and analytical rigour (Campbell 2003). Therefore, Atkins et al (2008) recommends appraising each research report to identify major gaps in the design and reviewing the findings based upon their insight. In this meta-synthesis it seems appropriate to critically appraise each study while considering the study findings.

Another consideration was that the similarities and differences between the methods can be confusing. Furthermore, there is limited guidance for identifying the best method to achieve meta-synthesis and the methods have not been evaluated for rigour. Therefore the researcher must make a judgement as to the best method to achieve the aim of their study (Atkins et al 2008, Noyes et al 2011).

In summary, when planning a meta-synthesis the researcher must bear in mind how to incorporate the context of the reported studies, whether to undertake critical appraisal, whether to use like as like studies or divergent methodologies. Despite these on-going debates it was decided that a meta-synthesis of qualitative findings would allow the focused exploration of existing studies through comparison and synthesis to provide new insight and knowledge into P-RNs' experiences of EOLC.

### **Rationale for choosing meta-ethnography**

The aim of this meta-ethnography is:

'To provide a new meaningful interpretation of the published research into P-RNs' experiences of end-of-life-care.'

This fits with an inductive method that allows P-RNs' experiences to emerge from research findings. Meta-ethnography was selected for several reasons. Firstly, it can help arrive at a higher order interpretation of P-RNs' experiences of EOLC. Secondly, it attempts to preserve interpretation and context by using original words from the study report findings to reveal P-RNs' experiences (Dixon-Woods et al 2004). Thirdly, determining if the research report's findings are directly comparable (reciprocal), in opposition (refutational) or create a line of argument, permits examination of the relationships between the studies while remaining true to the original findings. Fourthly, the original meta-ethnography method has been enhanced through the development of literature searching techniques and critical appraisal tools (Doyle 2003). Finally there are worked examples synthesising findings from studies using different methodologies such as phenomenological and grounded theory to refer to for guidance, such as Atkins et al (2008).

Meta-ethnography is defined as:

‘the synthesis of interpretive research. To preserve the uniqueness and holism that characterises qualitative studies’ (Noblit & Hare 1988 p2).

Hence, this involves integrating rather than aggregating data. In meta-ethnography research reports are identified and read, then synthesised using one of three methods. The first is reciprocal translation analysis (RTA), where the metaphors (themes and concepts) in each study report are identified and translated into one another by systematically comparing findings from each study, using a map or matrix. The second method is refutational synthesis, where the metaphors (concepts and themes) are identified and the contradictions between findings in individual reports are explored. The third type is line of argument (LOA). This involves building a general interpretation that links the findings of the separate studies into an explanation that moves beyond the research reports. Themes or categories are identified by using Glaser and Strauss’ (1967) constant comparison, to ‘put the similarities and differences into an interpretive order’ (Noblit & Hare 1988 p64). This builds a picture of the whole, such as a culture, organisation or experience. Noblit and Hare (1988) refer to the development of a ‘second level of synthesis’ (p64) in LOA but did not explain how this could occur (Barnett-Page & Thomas 2009). The original meta-ethnography method has been enhanced by several authors. Britten et al (2002) and Campbell et al (2003) evolved second level synthesis using Schutz’s (1962) notion of first, second and third orders of construction. First order constructs refer to everyday understandings of ordinary people, second order constructs refer to constructs of the social sciences and third order constructs interpret findings beyond the original results. Doyle (2003) added appraisal of qualitative data, specific inclusion and exclusion criteria for research reports and clarified data analysis through a matrix table.

## **The Method**

Meta-ethnography comprises seven phases, which overlap and are parallel during the process (Table 3.2). This meta-ethnography follows the phases proposed by Noblit and Hare (1988) and Atkins et al (2008).

### **Phase 1. Getting started**

The first stage is initial identification of the area of interest. Teaching P-RNs EOLC and supporting them through distressing experiences in the practice area

Table 3.2 Phases of meta-ethnography (Noblit & Hare 1988, Atkins et al 2008)

Phases of meta-ethnography (Noblit & Hare 1988, Atkins et al 2008)	This meta-ethnography
<p><b>Phase 1. Getting started</b> Identifying an interest that qualitative research might inform Research questions</p>	<p>P-RNs' experiences of end-of-life-care Purpose Questions to guide the meta-ethnography</p>
<p><b>Phase 2. Deciding what is relevant</b> Determining the focus Locate studies Inclusion/exclusion Quality assessment</p>	<p>Question to guide search strategy Search data bases Selected 8 research reports based upon inclusion criteria Critiqued each report for quality using CASP-qualitative tool</p>
<p><b>Phase 3. Reading the studies</b></p>	<p>Becoming as familiar as possible with the content and detail of the studies</p>
<p><b>Phase 4. Determining how the studies are related</b> List key metaphors/concepts used in each account Metaphors are juxtaposed An initial assumption about the relationship between the studies:  <ol style="list-style-type: none"> <li>1. Study findings are directly comparable as reciprocal translations</li> <li>2. Accounts stand in relative opposition to each other and are essentially refutational</li> <li>3. Studies taken together represent a line of argument</li> </ol> </p>	<p>Studies were read and reread with the aims of the synthesis in mind The accounts were similar and directly comparable so a reciprocal translation was performed</p>
<p><b>Phase 5. Translating the studies into one another</b> Maintains the central metaphors/concepts of each account in relation to those in other accounts</p>	<p>Arranged each paper chronologically, then compared the themes and concepts from paper 1 with paper 2 and 3 and so on Metaphors extracted and compared in juxtaposition in a table Repeatedly returned to the original papers to clarify the context while keeping an open mind for emerging themes</p>
<p><b>Phase 6. Synthesizing translations</b> Synthesis refers to making a whole from something more than the parts alone imply Translations are level one synthesis Metaphors compared to determine if some encompass those from other accounts Second level of synthesis analyse competing interpretations and translating them into each other</p>	<p>Metaphors grouped into themes The themes were read and reread and the original studies reviewed for context From this a model was developed that showed the relationship between the themes</p>
<p><b>Phase 7. Expressing the synthesis</b> Synthesis is an interpretation and explanation of the findings Translate the interpretations of one study into the interpretations of another Synthesis is complete when the assumptions have been checked, appropriate translations made and a text created that reveals the process and results</p>	<p>Themes were created into a conceptual map of the phenomenon Pre-registration nurses' experiences of EOLC: A conceptual map</p>

stimulated the purpose of this meta-ethnography:

The questions that guided this meta-ethnography were:

- What are P-RNs' preconceptions about end-of-life-care?
- What are P-RNs' experiences of end-of-life-care?
- Where do P-RNs' receive support when providing end-of-life-care?
- What are the rewards for P-RNs' when providing end-of-life-care?

## Phase 2. Deciding what is relevant

Noblit and Hare (1998) do not give any advice on locating studies therefore Atkins et al's (2008) recommendations were followed and a systematic search of data-bases was undertaken. Studies were then selected based upon the inclusion/exclusion criteria and appraised for quality.

### Locating relevant studies

A systematic search of the literature was conducted in October 2011 and April 2014. As for the search strategy in Chapter 2, an exploration of the grey literature and electronic data bases was performed. A supplementary search was conducted of publishers search engines and reference lists from each article were reviewed (Table 2.1). A combination of search strategies using thesaurus, free text, broad based terms and Medical Subject Headings (MeSH) were utilised to maximise yield (Booth 2008). The core search strategy was created as recommended by Cooke et al (2012) using the SPIDER approach (Sample, Phenomenon (PI), Design, Evaluation, Research), as outlined in the previous chapter. Qualitative research is not as clearly indexed as quantitative, therefore, free text search terms for qualitative research were used as recommended by Barrosso et al (2003) and Shaw et al (2004) (Table 3.3).

Table 3.3 Qualitative search terms

Sample: Student Nurses	Phenomenon: Palliative	Design: Data collection	Evaluation: Experience	Research: Qualitative
Baccalaureate	Dea*	Interview	Attitude	Ethnography
BSc	Dying	Focus group	Coping	Field-notes
Degree	End of Life	Observe*	Emotion	Field-studies
Diploma	Liverpool Care Pathway LCP	Participant observation	Experience	Grounded theory
Pre-registration	Palliative		Feeling	Hermeneutic
Nurse	Terminal		Lived	Lived experience
Student			Perception	Narrative
Undergraduate				Nursing research
				Phenomenology
				Qualitative

### Inclusion exclusion criteria

The following inclusion and exclusion criteria were applied.

Inclusion criteria:

- Qualitative exploration of P-RNs' experiences of end-of-life-care
- Were written in English from the UK, USA, Canada, Europe and Australia as these have similar healthcare systems and integrated EOLC into the general healthcare settings (Clark & Wright 2007)
- Conducted between 1986 and 2014, as studies before 1986 were deemed too old for temporal relevancy due to innovations in nursing practice and the movement to diploma/degree university based nursing education in the UK from 1986 (UKCC 1986)

Exclusion criteria:

- Publications related to symptom management or disease pathology
- Qualitative research into the education of doctors, allied health professionals, health care assistants, post qualification nurses
- P-RNs undertaking child or mental health branch, as their perspectives may be different to P-RNs caring for adults who are dying
- Quantitative studies of P-RN education as these do not reveal the depth of nurses' experiences of end-of-life-care

### Results

A total of 425 records were found, this reduced to 254 after the duplicates were removed (Figure 3.1). Each abstract was reviewed against the inclusion and exclusion criteria and the full research report read if it explored P-RNs experiences of EOLC. Eight qualitative studies were retained and are described in Table 3.4. Six studies used a phenomenological approach (Johnson 1994, Beck 1997, Loftus 1998, Cooper & Barnett 2005, Allchin 2006, Terry & Carroll 2008), one used grounded theory (Kiger 1994) while Parry (2011) utilised a descriptive qualitative methodology. Despite the differing methodologies the accounts were similar as they all explored P-RNs' experiences of EOLC and presented the findings as themes (Table 3.4). Therefore, the studies were appraised for quality.



Figure 3.1 Flow chart of search results for pre-registration nurses' experiences of EOLC

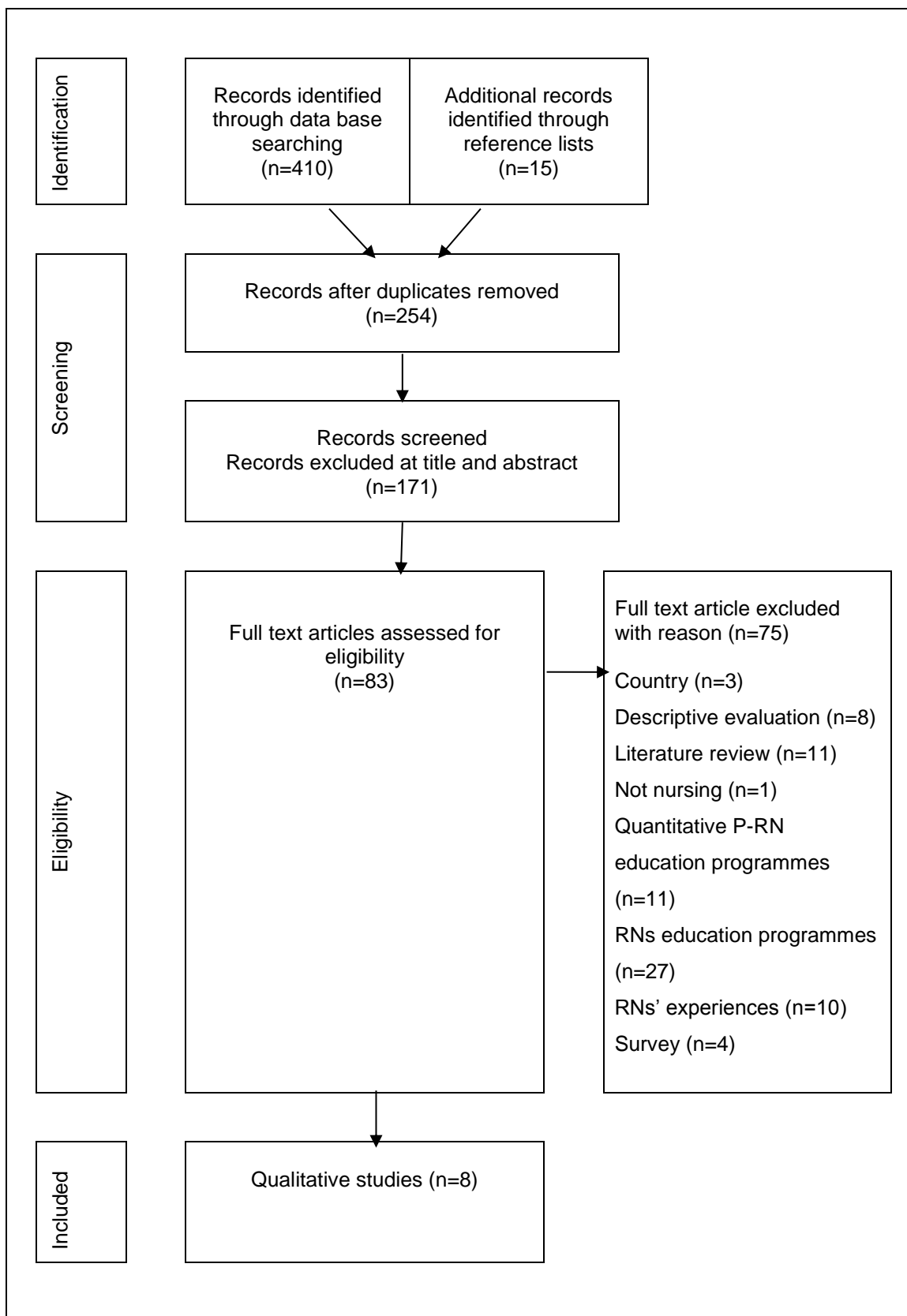


Table 3.4 Qualitative studies in the meta-ethnography

Reference	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Lofthus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allchin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
<b>Aim</b>	Investigates perceptions and experiences of death	Student nurses images and experience with death	Meaning of nursing students' experiences caring for dying patients	Understand the lived experience of third year student nurses caring for dying	Examine aspects of caring for dying patients in the first year	Identify students' experiences providing care for dying persons	Investigate first year nurses' encounters with patient deaths	Explore student nurses' experiences of a first death
<b>Methodology</b>	Hermeneutic Phenomenology	Grounded theory	Descriptive phenomenology	Phenomenology	Qualitative descriptive	Hermeneutic phenomenology	Descriptive phenomenology	Phenomenology
<b>Data</b>	Focus group	Interview	Written description	Interview	Reflective diary n=38	Interview	Focus group	Focus group
<b>Data Analysis</b>	Giorgi's method (2003)	Constant comparative Glaser & Strauss (1967)	Colaizzi's method (1978)	Van Manen's method (1990)	Colaizzi's method (1978)	Giorgi's method (2003)	Thematic analysis	Thematic analysis
<b>Country</b>	England	Scotland	USA	Scotland	England	USA	England	Wales
<b>Number</b>	8=adult	Total 24 13=adult; 3=child; 3=mental health; 5=learning disabilities	26=adult	6=adult	38=adult	12=adult	14=adult	5=adult
<b>Age</b>	18-20 years	17-36 years	18-55 years	Not given	19-46 years	Not given	Not given	21-44 years
<b>Gender</b>	Female=8	Female=21, Male=3	Not given	Not given	Female=35, Male=3	Female=12	Female=14	Female=5
<b>Ethnicity</b>	White=7, Black=1	Not given	Not given	Not given	Not given	Not given	Not given	Not given
<b>Marital Status</b>	1 married, 7 unmarried	Not given	Not given	Not given	Not given	Not given	Not given	Not given
<b>Programme and Year</b>	Diploma First	Diploma First, second, third	Baccalaureate Second, third	Diploma Third	Diploma First	Baccalaureate Third	Diploma First	Degree First
<b>Clinical Area</b>	Hospital, Hospice	Hospital	Hospital	Hospital	Hospital	Hospital	Hospital	Hospital

### Critique for quality

Whilst Noblit and Hare (1988) do not discuss whether there is a need to review the quality of the studies included, most qualitative researchers acknowledge that the rigour of qualitative studies should be taken into account in the synthesis process to ensure trustworthiness (Atkins et al 2008). The inclusion of studies that are flawed, distorted and difficult to interpret and hence of low quality will reduce the trustworthiness and credibility of the meta-ethnography (Campbell et al 2003, Dixon Woods et al 2004). The Critical Appraisal Skills Programme Criteria for Evaluating Qualitative Research (CASP-qualitative) (Public Health Research Unit 2006) was selected to guide the critical appraisal for several reasons. It has undergone rigorous development and testing (Public Health Research Unit 2006). The questions were considered broad enough to guide the appraisal of the rigour of the research methods, as well as the credibility and relevance of the findings (Table 3.5). Dixon-Woods et al (2007) and Atkins et al (2008) argue that it is impossible to create a universal procedural tool to test rigour of all qualitative methodologies, and a list of prompts such as CASP-qualitative is the best option.

Several adaptations were made to the tool. The Yes/No answer was limiting as the word count may have constrained the published reports, therefore, like Atkins et al (2008) and Barnett-Page and Thomas (2009) the option 'unclear' was incorporated (Table 3.5). In addition the CASP-qualitative, does not ask and phenomenology methodology were read to guide the appraisal (Campbell et al 2003, Atkins et al 2008). Finally, the advice of Dixon-Woods et al (2004) and Atkins et al (2008) was followed and each study report was also judged on the insightful findings that revealed P-RNs' experiences of EOLC.

The qualitative methodology and research design was appropriate to meet the aim of each of the eight studies. The rationale for using grounded theory was discussed by Kiger in an earlier publication (1993, 1994) (Table 3.5). Methods of data collection and analysis and the main findings were identified in the papers reviewed. Loftus (1998), Kiger (1994) and Allchin (2006) did not explain why some people chose not to take part. Possible reasons include not having undertaken EOLC or distressing experiences in their personal lives. Therefore, students with insightful experiences may not have contributed (Streubert-

Table 3.5 CASP Ten questions to help you make sense of qualitative research (Public Health Resources Unit 2006). Numbers refer to studies in Table 3.4

Screening questions	Yes	No	Unclear
<b>1. Was there a clear statement of the aims of the research?</b> What the goal of the research was? Why it is important? Its relevance?	1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8		
<b>2. Is a qualitative methodology appropriate?</b> Seeks to interpret/illuminate participants experience?	1,2,3,4,5,6,7,8		
<b>3. Was the research design appropriate to address the aims of the research?</b> If the researcher has justified the research design?	1,3,4,5,6,7,8		2
<b>4. Was the recruitment strategy appropriate to the aims of the research?</b> Has the researcher explained how the participants were selected? Why the participants were the most appropriate? Discussions why some people chose not to take part?	1,2,3,5,6,7,8 1,2,3,5,6,7,8 1,3,5,7,8	4 4 2,4,6	
<b>5. Were the data collected in a way that addressed the research issue?</b> Setting for data collection was justified? Clear how data were collected? Researcher has justified the methods chosen? Methods explicit? Discussed saturation of data?	1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8 1,3,4,5,6,7,8 1,2,3,4,5,6,7,8 4,6,7,8		2 1,2,3,5
<b>6. Has the relationship between researcher and participants been adequately considered?</b> The researcher critically examined their own role, potential bias and influence during: -formulation of the research question -data collection, sample recruitment and location	1,2,3,4,5,6,7,8 1,3,5,6,		2,4,7,8
<b>7. Have ethical issues been taken into consideration</b> Research explained to participants? Discussed informed consent, confidentiality? Effects of the study on participants during and after the study? Approval has been sought from the ethics committee?	1,3,5,7,8 1,3,5,7,8 8 1,3,5,6,7,8	2,4,6 2,4,6 1,2,3,4,5,6,7 2,4	
<b>8. Was the data analysis sufficiently rigorous?</b> In-depth description of the analysis process? How the themes/categories were derived from the data? How the data presented were selected? If sufficient data are presented to support the findings? To what extent contradictory data are taken into account? The researcher critically examined their own role, potential bias and influences during data analysis and data presentation?	1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8 1,3,5,6,7		2,4,8
<b>9. Is there a clear statement of findings?</b> Are the findings explicit? Is there adequate discussion of the evidence? Credibility of the findings (triangulation, respondent validation, more than one analyst? Discussed in relation to the original research question?	1,2,3,4,5,6,7,8 1,2,3,4,5,6,7,8 3,5,7 1,2,3,4,5,6,7,8		1,2,4,6,8
<b>10. How valuable is the research?</b> Discussed the contribution the study makes to existing knowledge i.e. policy, practice or research based literature? Identify new areas where research is necessary? How the findings can be transferred to other populations?	1,2,3,4,5,6,7,8 1,2,3,5,6,7,8 2,3,4,5,6,7,8	4 1	

Speziale & Carptenter 2010). The studies by Kiger (1994), Loftus (1998) and Parry (2011), did not acknowledge potential researcher bias. Therefore it is unclear if their perspective influenced data collection or analysis rather than allowing the data to emerge from the participants (Barbour & Barbour 2003). In addition, although the researchers provide a description of the process of analysis and developing analytical categories it is impossible to determine how rigorous or systematic their work has been in the research study (Barbour & Barbour 2003) (Table 3.5). Potential bias during data collection and analysis was addressed in a number of studies through reflection on personal sensitisation to the topic (Johnson 1994, Beck 1997, Cooper & Barnett 2005, Allchin 2006). Three studies verified their findings through participant checking (Beck 1997), verification with an independent colleague (Terry & Carroll 2008) and focus groups (Cooper & Barnett 2005), (Table 3.5).

Overall, despite some weaknesses none of the studies appeared to introduce significant bias into the findings. Rigour was achieved through the use of appropriate methodology and data collection methods. Credibility was achieved as the findings were meaningful and relevant to the exploration of P-RNs' experiences of EOLC. Therefore all eight studies were included in the meta-ethnography.

#### Study settings and designs

Six studies were undertaken in the UK (Johnson 1994, Kiger 1994, Loftus 1998, Cooper & Barnett 2005, Terry & Carroll 2008, Parry 2011) and two in the USA (Beck 1997, Allchin 2006). Sample characteristics were appraised as it has been suggested that gender, age and previous experience of death, illuminate the findings within a context for the reader (Morgan 1997, Terry & Carroll 2008, Finfgeld-Connett 2010). Studies explicitly selected P-RNs who had cared for the dying during first, second, third and fourth year of the programme. A comprehensive summary of the samples' characteristics were presented by Johnson (1994) and Parry (2011). Some studies did not present the age range (Loftus 1998, Allchin 2006, Terry & Carroll 2008) or gender (Beck 1997, Loftus 1998), while ethnicity was identified in one study only (Johnson 1994). Beck (1997) purposely omitted participants' background information to maintain confidentiality which may have reduced the insight into P-RNs' experiences (Table 3.4).

Students' experiences were elicited through focus groups (Johnson 1994, Cooper & Barnett 2005, Terry & Carroll 2008, Parry 2011) or one to one interviews (Kiger 1994, Loftus 1998). Cooper and Barnett (2005) analysed data from reflective journals and findings were then explored through focus group interviews. Beck (1997) collected data solely written accounts (Table 3.4).

### **Phase 3. Reading the studies**

As recommended by Noblit & Hare (1988) and Atkins et al (2008) each research report was read in its entirety to understand the whole study and become familiar with the content and detail and to begin the process of extracting metaphors/emerging themes. The synthesis aim was kept in mind and the original papers frequently reviewed to clarify the context. Campbell et al (2003) suggest that the order in which studies are compared may influence the synthesis. Therefore, Atkins et al's (2008) advice was followed and the studies were sorted into chronological order so that the oldest was read first.

### **Phase 4. Determining how the studies are related**

The relationship between the studies was explored to determine if they were reciprocal, refutational or in a line of argument (Noblit & Hare 1988). As Noblit and Hare (1988) recommend, each study was read and metaphors grouped into themes that were juxtaposed in tables. In reciprocal studies the findings are directly comparable. These eight studies were considered reciprocal as all studies included P-RNs working in a hospital setting and the accounts were similar. None of the accounts were in opposition to each other as in refutational studies. In addition, there was no evidence of a developing theory of a culture of P-RNs' experiences as in a line of argument.

### **Phase 5. Translating the studies into one another**

There is little guidance from Noblit and Hare (1998) about how to translate the studies into one another, therefore Atkins et al's (2008) advice was followed. Data were extracted by reading the interpretations and supporting raw data in each study. Interpretations relevant to the guiding questions for this meta-ethnography were listed in a matrix as interpretive metaphors. Reciprocal translation was performed, through reading the next paper and extracting the researcher's interpretations. Once relevant interpretations had been identified These were either recorded in juxtaposition to similar metaphors, or a new

metaphor was created. This sequence was followed with each paper.

## **Phase 6. Synthesizing translations**

Once the translation of interpretations from one study into another was completed an array of metaphors had emerged. Synthesising the translated metaphors occurred through reading and reviewing the metaphors. Similar ones were merged and collapsed into themes for example 'Metaphors for preconceptions,' and 'Metaphors for the emotional impact upon P-RNs.' Atkins et al (2008) suggest this pragmatic approach assists in the synthesis but could constrain the emergence of new themes. They addressed this by two reviewers undertaking the data analysis, in this meta-ethnography the results were discussed and reviewed with two research supervisors.

Eleven themes emerged: Preconceptions; Culture that promotes good death; Culture that allows a poor death; Emotional impact upon P-RNs; Reasons for the emotional reaction; Communication with patients and their family members; Performing last offices; Ways of supporting P-RNs; Lack of support for P-RNs; Learning experience and Strategies that may improve the student experience. Themes are presented with the metaphors in tables, grouped according to the four questions that guided the meta-ethnography. Context is important, lending credibility and weight to primary studies (Atkins et al 2008). Thus the following information is provided: year of training and previous experience of death prior to the programme. However, limited background information made it difficult to present the findings according to gender, age and the context of the type of clinical area. For ease of reading, these studies will be referred to by the numbers in Tables 3.6-3.16.

### What are pre-registration nurses' preconceptions' about end-of-life-care?

Studies identified P-RNs' preconceptions of caring for patients who were dying (Table 3.6). One study explicitly sought preconceptions through interviews that allowed probing and clarification. This revealed that first year participants expected 'it to be difficult,' when seeing patients suffer and viewed death as 'the bad of nursing' (2). First and third year students expected 'patients to get better' when they started nursing (4,7), in contrast some thought that 'everyone dies' (7). Some students 'felt unprepared,' (4) although one study found first year students 'felt prepared until they experienced a death, then felt unprepared' (8).

Table 3.6 Metaphors for preconceptions

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allchin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
Expectations positives				'patients get better' (p645)			'everyone is cured' (p763)	
Expectations negatives		'expected to be difficult' (p680)					'everyone dies' (p763)	'own perception versus reality' (p450)
Death is bad		'the bad of nursing' (p680)						
Unprepared to care				'unprepared' (p645)				'felt prepared until experienced death then felt unprepared' (p450)
Previous experience of death	'prior to nursing' (p137)	'family death' (p680)				'family' (p115)	'Health Care Assistant' (p744)	'no evidence being Health Care Assistant made students better prepared' (p450)



Some had personal experiences of death 'prior to nursing' as family members (1,2,6) or 'a health care assistant' prior to nursing training (7,8). There was no evidence being a health care assistant (HCA) prepared students to deliver EOLC (8). Previous experiences and preconceptions about caring for the dying were not requested in the written accounts (3) and may not have been discussed during the focus group interviews (5). Therefore, it was unknown how P-RNs' preconceptions and previous experiences affected their ability to provide EOLC or if preconceptions changed over time.

### What are pre-registration nurses' experiences of end-of-life-care?

Six themes emerged that revealed P-RNs' experiences of EOLC: 'Culture that promotes good death,' 'Culture that allows a poor death,' 'Emotional impact upon P-RNs,' 'Reasons for the emotional reaction,' 'Communication with patients and family members' and 'Performing last offices.'

#### *Culture that promotes good death*

Studies revealed aspects of care that were perceived as promoting a good death (Table 3.7). It was suggested that 'extra special care' was reserved for dying patients, while others explained that the care entailed 'holistic psychosocial care' (3,7). Third year students identified how RNs 'acted as an advocate for the patient' and allowed patients to 'die with dignity' (4). This was delivered in hospices by 'registered nurses through open awareness' (1) and the family was considered an 'integral part of care,' (1,3,8). Students explicitly expressed their desire to promote a good death through 'relieving pain' (3,5). These participants were from hospital and hospice settings and were first, second and third year nurses. Other studies did not report this, an explanation may be that experiences of good death were not explored during the interviews (2,6).

#### *Culture that allows a poor death*

There were also examples of cultures that allowed a poor death (1,3,4,5,7,8) (Table 3.8). P-RNs perceived the doctors' role was key to this as 'they made the decisions' (1,4), such as 'continued with unnecessary tests' (1) and 'interventions' that technicalised death (4). This may have been because they perceived 'death is a failure' (1). Alternatively, some students thought doctors were not effective and 'did not do enough to stop patients' pain' (3,4).

Table 3.7 Metaphors for culture that promotes good death

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allichin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
Holistic care			'comfort physically mentally and spiritually' (p413)	'nurses acted as an advocate. Die with dignity' (p646)	'extra special care' (p426)		'psychosocial care' (p762)	
Stop suffering			'relieve pain' (p413)		'stop suffering, pain' (p425)			
Family	'open awareness' (p1157)		'integral part of care' (p413)					'family were important' (p451)

Table 3.8 Metaphors for culture that allows a poor death

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allichin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
Doctors unnecessary treatment	'unnecessary tests' (p1157)			'continue interventions' (p644)				
Death is failure	'death is failure' (p1157)		'not doing enough to stop patients pain' (p411)	'doctors not effective' (p644)				
Nurses felt powerless	'little control' (p1157)		'not have enough clout' (p412)	'powerless' (p643)	'powerless' (p426)			
Holistic care not given							'failure to provide holistic care' (p764)	
Family not supported							'abandonment of relatives' (p762)	
Lack of respect	'laughing or seeming uncaring' (p1157)			'mentioned in passing' (p645)	'not ensuring privacy' (p411)		'less than optimum respect and dignity' (p762)	'using wet wipes to save time' (p450)

Sometimes both students and RNs felt 'powerless' to control patients' symptoms (1,3,4,5). These findings were drawn from examples in hospital wards, by first, second and third year nurses. Students identified examples of 'failure to provide holistic care' and 'abandonment of relatives' (7). There was a reported lack of respect with examples of nurses 'laughing or seeming uncaring' (1); 'not ensuring privacy' (5); 'death mentioned in passing' during reports (4); demonstrating a dismissive attitude with 'less than optimum respect and dignity' towards the deceased patient (7) and 'using wet wipes to save time' during last offices (8). It was suggested that this might be due to the busy ward and inexperienced RNs (7). The other studies did not explore possible reasons for a culture that allows a poor death as the focus was upon P-RNs rather than patients' experiences (1,3,4,5,8). Two studies did not reveal any examples of poor death, this may not have been explored or alternatively not experienced in the clinical area (2,6).

#### *Emotional impact upon P-RNs*

All the studies identified an emotional impact when caring for the dying, suggesting this is a consistent experience for P-RNs (Table 3.9). EOLC was 'emotionally draining,' and 'emotionally difficult' (2,3,7). Students expressed 'shock,' (1,4,5,7,8), 'guilt,' (1,4,5,7) and 'sadness'(2,3,4,5,6,7). A frequent emotion was fear, expressed through the terms 'frightened,' 'terrified, awful' and 'horrific nightmare' (1,2,3,4,8). These are powerful metaphors that emphasise the impact of caring for dying patients upon P-RNs. Some expressed 'anger at themselves, doctors' (3,4) and 'towards the nurses' lack of respect' (8). 'Anxiety' was mentioned in four studies (3,5,6,7). Other words expressed students 'helplessness' and 'frustration' (3,4,5,6,7). It was not explicit in these studies if these responses were influenced by previous experiences or because it was a new experience. In addition these students were in their first, second and third year of training, suggesting the emotional response may occur at any stage of the programme of study.

Studies identified how students managed their emotions in the CLE. Some students 'felt their emotions should not affect their ability to work' (2,5) and 'keep things as normal as possible for patients' (7). 'Distancing tactics' were used by 'avoiding' a patient (1,3,5,7), although students considered 'detachment' was an appropriate way to respond professionally (5). Other

Table 3.9 Metaphors for the emotional impact upon P-RNs

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allchin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
Emotionally difficult		'draining' (p682)	'difficult' (p410)				'difficult' (p763)	
Sadness		'sad' (p683)	'sad' (p410)	'upset' (p644)	'sadness' (p425)	'sadness' (p115)	'sadness' (p763)	
Shock	'shock' (p1156)			'disbelief' (p644)	'shock' (p425)		'shock' (p762)	'shock' (p450)
Guilty	'guilt' (p1158)			'guilt' (p644)	'guilt' (p426)		'guilty' (p763)	
Frightened	'frightened' (p1158)	'terrified,' 'awful' (p681)	'afraid' (p410)	'frightening,' 'horrific' (p644)				'fear,' 'horrific' (p450)
Anger			'anger' (p410)	'anger' (p644)				'angry' (p450)
Anxious			'anxious' (p410)		'anxiety' (p426)	'anxiety' (p115)	'anxiety' (p763)	
Helpless			'helpless' (p411)	'frustrated' (p646)	'inadequacy' (p426)	'hesitant' (p114)	'uncertainty' (p763)	
Distance at work	'avoiding patient' (p156)		'distancing, withdrawing' (p410)		'distancing appropriate' (p427)		'avoidance' (p763)	
Hide emotions at work		'emotions should not affect work' (p683)			'hide emotions' (p427)		'keep things normal for patients' (p763)	'no avoidance' (p452)
Emotions at home		'tears' (p682)		'rash, not sleeping, not eating, shaking' (p645)	'cry at home' (p428)	'crying when driving home' (p115)	'not sleeping, could not stop thinking about it' (p763) 'worried for the mental health of students' (p763)	'need to cry' (p451)

studies did not report how participants managed their emotions during a shift (4,6,8). The emotional impact continued after leaving the clinical areas. Some students, 'could not stop thinking about it' (7), and were 'crying' after work (2,5,6,8). Physical signs of stress were identified among third year nurses such as 'rash, not sleeping, not eating and shaking' (4). One investigator was 'worried for the mental health and safety of students' (7). The researchers discussed the severity of these extreme examples rather than the frequency of occurrence. So it was unclear if all students experience these extreme reactions or a few participants.

#### *Reasons for the emotional reaction*

There were several reasons for students' emotional reactions (Table 3.10). These include the 'first encounter with death' (2,5,6,7,8). Some students found 'young death was more traumatic than older patients' as they were able to rationalise death among older people (1,5,7). Sudden death rather than expected death was found to be 'more distressing' (1,2,4,5,7,8). This was reported by first, second and third year students in hospitals suggesting an emotional reaction may occur irrespective of the year of training.

A second reason put forward was a bond between the student, patient and family, suggesting this is a key influence (1,2,3,4,5,6,7,8). The bond was influenced by the 'patients' personality' (4,5). In addition, 'care of the family was important' (1,3,8) and a 'simple thank you from relatives could provoke an emotional response,' (8). Students 'worried about the patient' (1,2), and were upset if 'absent' when the patient died (1,4,6) and 'severing the strong relationship when the patient died' affected the student (7). The accounts revealed that 'seeing the patient suffer' also affected students (3,4,5,6). Interestingly some students felt guilty as they 'were not upset' when a patient died (1,2,4). One reason suggested for this was they had 'not known the patient very long' (4), so may not have built an emotional attachment. This suggests the emotional impact is different for each individual and is influenced by the context, meaning and individual patient.

A third reason for the emotional impact was that the patient's illness and death had 'personal resonance' and 'flashbacks' (2,6,7,8) to memories of 'grandfathers' (2,6), 'husband' (7) and 'own relatives' (8) deaths. This was not revealed in other studies that may not have investigated this during focus

Table 3.10 Metaphors for the reasons for the emotional reaction

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allchin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
<b>First death</b>		'first death' (p682)			'first death' (p427)	'death' (p115)	'first death' (p761)	'first death' (p450)
<b>Patients age</b>	'expected old rather than younger' (p1158)				'rationalise older patients, but younger person challenged their beliefs' (p426)		'young death was more traumatic than older' (p763)	
<b>Sudden death</b>	'how easy death occurred' (p1158)	'sudden death' (p682)		'sudden death' (p645)	'sudden death' (p426)		'sudden death' (p763)	'deterioration' (p450)
<b>Bond with patient and family</b>	'worried about patient' (p1157) 'care of the family was important' (p1158)	'worried about the patient' (p682)	'wondered what kind of person' 'family needs' (p411)	'close meaningful relationship' (p644)	'degree of involvement and the patients personality' (p425)	'empathetic feelings for the dying person and family' (p115)	'severing of the strong relationship' (p763)	'thank you from patients relatives' (p451)
<b>Absent when patient died</b>	'leaving a patient' (p1158)			'being away' (p644)		'absent' (p115)		
<b>Patient suffering</b>			'get weaker' (p410)	'patient suffer' (p644)	'patient suffering' (p425)	'patients' quality of life' (p115)		
<b>Not being upset</b>	'not upset' (p1158)	'felt should have been more affected' (p682)		'not upset had not known patient long' (p644)				
<b>Personal resonance</b>		'grandfathers death' (p682)				'grandfathers death' (p115)	'husband's death' (p763)	'own relatives' (p451)
<b>Feeling inadequate</b>			'personal inadequacy' (p414)	'performance could have been better' (p645)	'feeling of inadequacy' (p426)		'questioned their actions' (p763)	'inadequate' (p451)
<b>Do not resuscitate policy</b>	'moral dilemma' (p1157)	'doctors had not worked hard enough' (p168)		'did not understand' 'moral dilemma' (p645)	'questioned the decision' (p427)			

groups, alternatively participants may not have wanted to reveal personal experiences (1,3,4,5). Written accounts focus upon caring for a dying patient thus potentially inhibiting the discussion of personal experiences (3). None of the studies explored how these experiences influenced the care given to patients and their family members.

A final reason for the emotional impact was students' 'anxiety,' and feeling 'inadequate' (3,4,5,7,8) due to a lack of experience caring for the dying. These were first (3,5,8) and third (4) year nursing students. Finally, resuscitation was a concern as first year (5) and third year (2,4) students 'did not understand' the do not resuscitate policy, and some believed 'doctors did not try hard enough' to resuscitate (2). Thus two investigators acknowledged the 'moral dilemma' that occurs during resuscitation and do not resuscitate discussions (1,4).

#### *Communication with patients and family members*

Communication with patients and family members was a consistent cause of emotional distress mentioned in all studies (Table 3.11). Students identified that communication was 'difficult' (1,2,3,4,5,8). Several reasons for this were identified. A widespread concern was that students 'did not know what to say' to relatives and patients (1,2,3,5,6,7). They were also unsure what 'they or the patient and family knew about diagnosis' (1,2,3,6). One investigator explained that a student who had worked in a hospice expressed a 'preference for open context communication' (1). Yet students 'had to get on with it' and communicate despite their inexperience (2,5,6,7). One investigator found students used their instinct to guide their conversation (7). Others reported 'being there rather than doing' by quietly sitting and holding the patients hand, this suggests non-verbal communication is an important intervention (1,3,4,7,8). Less commonly, some students found 'in reality communication was less dramatic' (2), and 'awkwardness seemed to subside when they were able to care for a patient for more than one day' (6). Also 'patients' anger' about diagnosis being directed towards the student nurse was mentioned (2,3). However, there was no discussion as to how the student was supported when communicating with angry patients.

#### *Performing last offices*

Performing last offices was seen as 'carrying on the care after death' and when this was not possible students' experienced an 'incomplete feeling' although

Table 3.11 Metaphors for communication with patients and their family members

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allchin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
Difficult	'difficult' (p1156)	'difficult' (p681)	'difficult' (p410)	'difficult' (p644)	'difficult' (425)			'difficult' (p451)
Did not know what to say	'did not know what to say to relatives' (p1158)	'inexperienced' (p681)	'lacked the right words' (p411)		'unsure what to say' (p426) 'inexperienced' (p426)	'uncertain' (p114)	'uncertainty over how to behave' (p763)	
Lack of information	'not always in control of what they (student) or the patient knew' (p1156)	'being in the dark' (p681)	'dying patients were unaware of their prognosis' (p412)			'lack of knowledge about whether patient and family knew diagnosis or prognosis' (p114)		
Open awareness	'preference for open context communication' (p156)							
Had to communicate		'essential component in reality communication was less dramatic' (p681)			'had to communicate' p426)	'awkwardness seemed to subside when caring for more than one day' (p115)	'had to try to deal with the relative alone' (p762) 'used instinct' (p765)	
Patient's emotions		'patient was angry' (p681)	'patient was angry' (p411)					



Table 3.12 Metaphors for performing last offices

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allchin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
Important to students	'carried on the care after death When not possible had an incomplete feeling' (p1157)	'closure through performing last offices' (p682)						
Supported					'talking to the dead patient was helpful' (p427)		'laying out the body respectfully' (p762)	
Unsupported	'left alone with the body' (p1158)				'talking to the dead patient caused discomfort' (p427)		'rigor mortis had set in before last office' (p763)	'how the person looked when dead' (p450) 'lack of respect performing last offices' (p450)
Finality of death					'covering the persons head with a sheet, reinforced the finality of death' (p427)			'covering the persons head with a sheet, reinforced the finality of death' (p450)

this is not explained (1). Another study explained it 'gave students closure' (2) (Table 3.12). One investigator identified that students felt supported when 'laying out the body respectfully' conversely, a student felt unsupported when 'rigor mortis had set in before last offices' (7), or when 'left alone with the body' (1). The 'person looked different' from what was expected and 'the lack of respect' for the patient (8) made performing last offices a bad experience. In one study some students found 'talking to the dead caused discomfort' for others 'it was helpful' (5). Finally 'covering the persons head with a sheet, reinforced the finality of death' (5,8). However, performing last offices was not discussed in three studies (3,4,6). This may not have been explored in written accounts (3) or interviews (2), alternatively the individuals may not have performed last offices.

#### Where do pre-registration nurses receive support when providing end-of-life care?

Two themes emerged that related to sources of support for P-RNs' when providing end-of-life-care: 'Ways of supporting P-RNs' and 'Lack of support for P-RNs.'

##### *Ways of supporting P-RNs*

The findings revealed strategies students found supportive (1,2,4,5,6,7,8) (Table 3.13). Some simply identified the RN/mentor was 'supportive' (2,7,8). Supportive strategies included RNs using their knowledge by 'explaining and encouraging' with reassurance that 'procedures were performed correctly' (1,4,5,6), or 'registered nurses who were not afraid to show their emotions' (1) and were 'good professional role models' (7). Students caring for a dying patient for 'more than one day' allowed continuity and development of a bond, which was supportive (6). These are important points, despite arising from single studies. Lecturers and clinical instructors also 'provide important support' (2,6,7). One study concluded that 'regardless of how supportive their mentors were, all the students needed to talk to someone else' (8), usually 'friends and family' (2,4,5,8).

##### *Lack of support for P-RNs*

The findings revealed students may experience a lack of support from RNs (4,6,7,8) (Table 3.14). Some RNs 'failed to recognise the signs that the student was feeling shocked or distressed' (7). A dominant finding was students 'not

Table 3.13 Metaphors for ways of supporting P-RNs

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allichin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
RNs support		'supportive' (p682)					'supportive' (p762)	'supportive' (p450)
RN knowledge, encourages	'explaining and encouraging' (p1156)			'procedures were performed correctly' (p645)	'reassurance' (p427)	'knowledge, expertise, reflection' (p115)		
Good role models	'nurses not afraid to show their emotion' (p1156)						'good professional role modelling' (p762)	
Continuity of care						'more than one day' (p115)		
Lecturers		'lecturers' (p682)				'clinical instructor' (p115)	'link lecturer' (p762)	
Family/friends		'friends and family' (p682)		'friends and partners' (p645)	'peers' (p428)			'needed to talk' 'mother' (p451)

Table 3.14 Metaphors for lack of support for P-RNs

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allichin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
Lack of Support				'no support' (p645)			'failed to recognise student distressed' (p763)	'feel unpopular' (p450)
Not allowed to express feelings				'sent away for tea' 'procedures rather than feelings' (p646)		'no opportunity to talk' (p115)	'never asked how do they feel' (p762)	'fear would be marked down' (p450)
Inconsistent support							'not supported during each death' (p762)	'some mentors supported' (p450)

being allowed to express their emotions' (4,6,7,8). There was 'no opportunity to talk on the ward' (6,8), not asked 'how do you feel' (7), were 'sent away for tea' (4), or mentors focusing upon 'procedures rather than the students feelings' (4). One student felt 'unable to express emotions for fear, they would be marked down' (8). There was inconsistent support as 'some mentors supported students better than others' (8) and 'students were not supported during each death'(7). Another was made to 'feel unpopular' with her mentor and the other nurses because she had asked to wash a person with flannel and soap rather than wet wipes (8). This may not have been experienced by the participants of other studies (1,2,3,5).

### What are the rewards for pre-registration nurses when providing end-of-life-care?

Two themes emerged that identified rewards for P-RNs' when providing end-of-life-care: 'Learning experience' and 'Strategies that improve the student experience.'

#### *Learning experience*

Despite the emotional effects, some students perceived they had learned to provide EOLC (Table 3.15). Firstly, some students 'learned knowledge, skills and attitudes' (1), to 'help people to get well and also to die' (3), so that perceptions of 'death changed from being bad to rewarding' (2). Whilst this was the only study to follow the same group of nurses throughout their training (2), a change in perception was also identified in other studies (1,3,6). Secondly, through their 'professional development' (1,2,3,6,7,8) by understanding the 'ethos' or 'essence of nursing' (1,2,6), 'power of caring' (3), and the importance of 'patient dignity' (8). Finally, personal development occurred through an 'acceptance of their own feelings' (1) and caring for dying patients and their families was an opportunity they were 'glad to have' as this 'helped to ease anxiety about when they registered' (6). They learned to be less judgemental and 'care unconditionally' (3) The other investigators did not reveal any learning or rewarding experiences (4,5).

#### *Strategies that may improve the student experience*

Strategies that may improve the student experience emerged (Table 3.16). Students requested 'support' and 'guidance' (1,2,6,7), although the type of support was not explained. There was also a request for RNs to 'model

Table 3.15 Metaphors for learning experience

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allichin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
<b>End-of-life-care</b>	'knowledge, skills, attitudes and experiences' (p1158)	'death changed from being bad to rewarding' (p683)	'they help people to get well but also to die' (p413)			'complex and challenging' (p115)		
<b>Professional</b>	'professional development' 'ethos of nursing' (p1158)	'essence of nursing' (p682)	'the power of caring' (p414)			'a nurse' (p115)	'professional' (p762)	'patient dignity' (p451)
<b>Personal</b>	'acceptance of their own feelings' (p1157)		'care unconditionally' (p413)			'glad to have,' 'helped to ease anxiety about when they registered' (p115)		

Table 3.16 Metaphors for strategies that may improve the student experience

Metaphor	Paper 1. Johnson (1994)	Paper 2. Kiger (1994)	Paper 3. Beck (1997)	Paper 4. Loftus (1998)	Paper 5. Cooper & Barnett (2005)	Paper 6. Allichin (2006)	Paper 7. Terry & Carroll (2008)	Paper 8. Parry (2011)
<b>Support/ guidance</b>	'support' (p1160)	'support,' 'guidance' (p683)				'support' 'reassurance' (p115) 'guidance' (p115)	'supported' (p764) 'modelling' (p763)	
<b>Knowledge /skills</b>	'theoretical,' 'Small rather than large groups' (p1157)	'educational goals' (p683)	'knowledge and skills' (p413)			'knowledge' (p115)	'training' (p763)	'training' (p451)
<b>Share their emotions</b>					'share personal feelings with nurses' 'dispel myth that a good nurse is in control of feelings' (p428)			

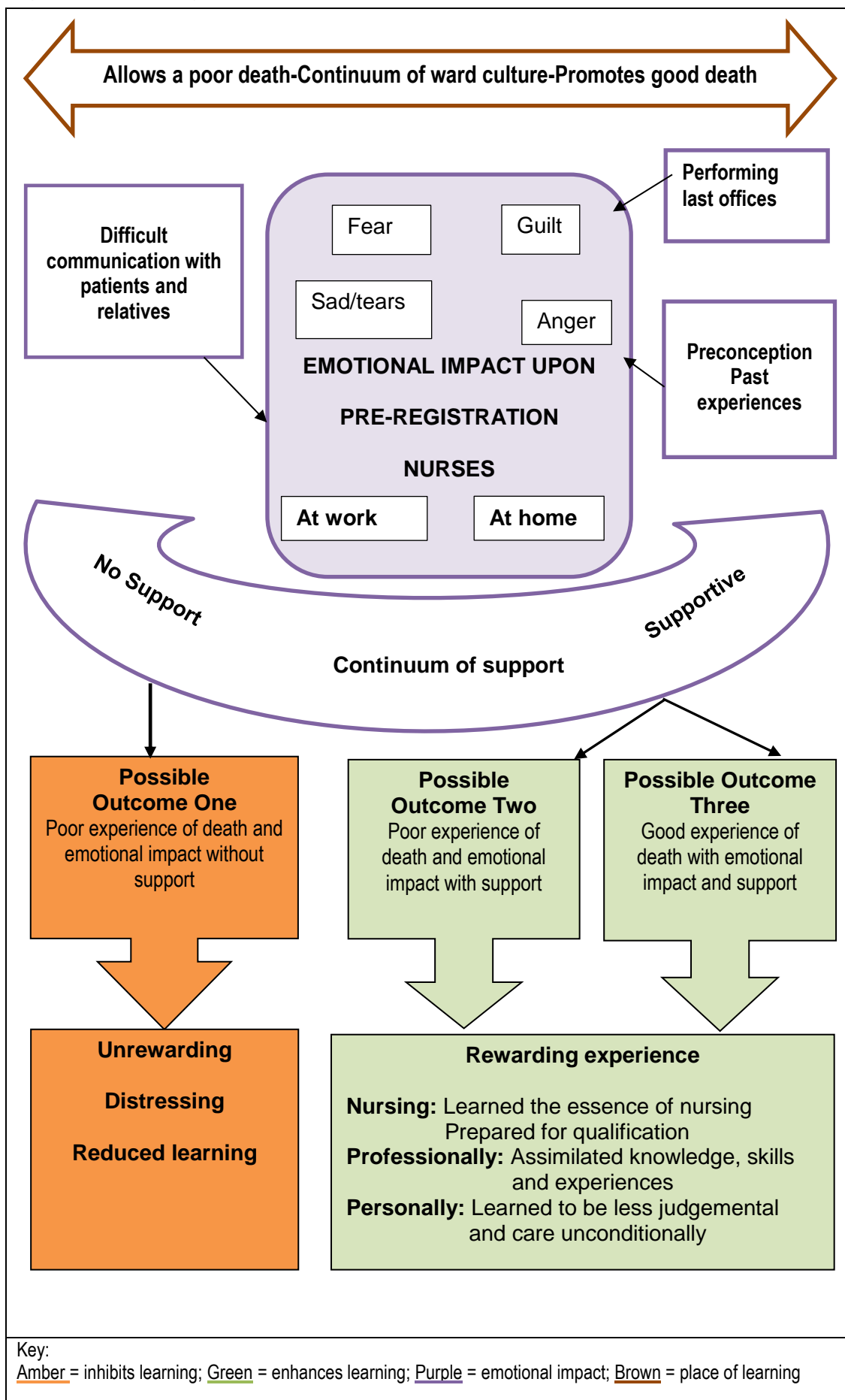
professional behaviour' (7) and provide 'reassurance' (6) that students nursing skills were satisfactory. Knowledge/skills also emerged through the need to set 'clear educational goals for students' (2) and receive 'theoretical knowledge' and 'training' (1,3,5,6,7,8) about EOLC, communication, last offices and managing the emotional impact. Also to 'understand the decisions made about 'do not resuscitate' guidelines (5). One study suggested a preference for 'sessions in small rather than large groups' (1). Finally, students 'sharing personal feelings with nurses to help legitimise their concerns' about providing EOLC (5) appeared to help manage the emotional impact. Loftus (1988) did not suggest anything to improve the student experience in the findings (4).

### **Phase 7. Expressing the synthesis**

The purpose of this meta-synthesis was to develop a meaningful interpretation of the published research into P-RNs' EOLC experiences. Employing a 'reciprocal translation' revealed eleven themes that were synthesised into a conceptual map of 'Pre-registration nurses' experiences of EOLC' (Figure 3.2). The conceptual map represents the relationships between the metaphors that influenced P-RNs' experiences. These relationships potentially result in an outcome that is unrewarding with reduced learning (Possible Outcome One). Alternatively, with support, the outcome may be a rewarding experience (Possible Outcome Two and Three). The synthesis of the eight studies showed a range of common experiences and concerns, which were influenced by a combination of P-RNs' preconceptions, the ward culture, sudden death, difficult communication with patients and their family members, performing last offices and the support delivered. No particular model of good practice emerged, as there were examples of cultures that promoted a good death or conversely allowed a poor death to occur. In addition, P-RNs' experiences varied between receiving support or a lack of support from RNs when providing EOLC.

Central to the model is the potential emotional impact for PRNs (Figure 3.2). This theme was common to all eight studies (Table 3.10) Studies by James (1992) and Smith (1992) also revealed the emotional impact of working with the dying and their families. In addition, there is some evidence that suggests that, not learning to manage emotions may contribute to the attrition of P-RNs (Deary et al 2003, Crombie et al 2013). However, it is unclear how previous

Figure 3.2 Pre-registration nurses' experiences of EOLC: a conceptual map



personal and professional experiences influence how P-RNs learn to manage the emotional impact of providing compassionate EOLC. Therefore, further research into this area is required.

Another key component of the model was that communication with patients and relatives is challenging, as P-RNs did not know what to say in response to questions, grief and anger (1,2,3,4,5,6,7,8) (Table 3.11). As a consequence P-RNs may avoid the dying and their relatives. This tension needs to be resolved in order to facilitate a good peaceful death for the patient and a rewarding experience for P-RNs, yet it is unclear how communication skills were learned in these studies. Therefore, more research is needed exploring how P-RNs learn to communicate with the dying and their relatives.

Three possible outcomes emerged from these experiences of caring for the dying and their relatives (Figure 3.2). These appear to be influenced by perceived support from RNs. In Outcome One P-RNs experience a poor or traumatic death. This may be due to patient's suffering (3,4,5,6), sudden or unexpected death (1,2,4,5,7,8), first experience of death/last offices (1,2,5,6,7,8), or a young person dying (1,5,7). In addition, memories of personal family experiences of people dying may impact upon the experience (2,6,7,8). However, P-RNs do not feel supported during these potentially traumatic situations (4,7,8). P-RNs may lack understanding about the management of differing disease trajectories and the rationale for do not resuscitate decisions (1,2,4,5). One possible interpretation is that when RNs do not share their knowledge, P-RNs may feel undervalued and unsupported (Chesser-Smyth 2005, Bradbury-Jones et al 2011). Indeed, there was a request by P-RNs for more education/training in EOLC (1,2,3,5,6,7,8). Also P-RNs may not be given the opportunity to talk about their emotions (4,6,7,8), and reflect upon the event which may inhibit developing strategies to manage their emotions. It has been suggested that if P-RNs are professionally and emotionally unsupported they may develop inappropriate coping strategies such as blocking conversations, avoiding patients and relatives, binge eating and drinking too much alcohol (Hamill 1995, Thomas et al 2012). Thus a lack of support may lead to an unrewarding experience, distress and reduced learning.

In contrast, with support mechanisms from RNs as seen in Possible Outcomes Two and Three the experience may be rewarding and learning enhanced



(Figure 3.2). In Outcome Two P-RNs also encountered a poor death with patients suffering (3,4,5,6), sudden unexpected death (1,2,4,5,7,8), first experience of death/last offices (1,2,5,6,7,8) or a young person dying (1,5,7). Outcome Three is situated in the context of a good peaceful death through nurses and doctors collaborating to promote symptom management and supporting family members (1,3,4,5,7,8). One possible interpretation is that promoting a good peaceful death may be more achievable when a person is older or the prognosis is known as there may be more opportunity to deliver symptom control and talk to relatives as in the Standards for End-of-Life Care (NICE 2013). It has been argued that the unpredictable nature of death may always be a threat to effective care, although anticipatory planning may overcome these difficulties (Griggs 2010). Nevertheless, these are also potentially emotionally traumatic situations as this may be the student's first experience of EOLC (2,5,6,7,8) or have resonance to a previous personal experience (2,6,7,8). Although the continuity of care with patients and family was perceived as supportive (6), P-RNs may develop an emotional bond that may contribute to an emotional response (1,2,3,4,5,6,7,8).

In contrast to Outcome One, both Outcomes Two and Three resulted in a rewarding experience when a supportive RN shared their knowledge and encouraged P-RNs to provide EOLC (1,4,5,6). In addition, observing RNs treating patients and relatives with dignity and respect may also be supportive (1,7). P-RNs also talked with their friends and family for support (2,4,5,8). Talking with friends has been considered an important form of support in other studies (Kevern & Webb 2004, Roberts 2008). However, the content of the interaction was not explored and it is unclear if there was an opportunity to reflect and process what happened.

In conclusion, it has been suggested that students learn at the side of RNs in a community of learning (Lave & Wenger 1991, Spouse 2001b). This meta-synthesis reveals that when RNs shared their knowledge this was perceived as supportive but this may be dependent upon the individual RNs. However, some students described mentors as supportive but did not explain why (2,7,6). The conceptual model developed from this meta-ethnography illustrates factors involved in P-RNs' experiences of delivering EOLC (Figure 3.2). However, none of the studies synthesised focused on factors that enhance P-RNs learning

EOLC alongside RNs. For examples it is unclear how P-RNs learn to manage the emotional impact of caring for the dying. Moreover, there is little exploration of how P-RNs learn to communicate with the dying and their relatives or how previous personal and professional experiences influence learning EOLC. More research is needed therefore to investigate P-RNs perceptions of how learning end-of-life-care could be enhanced in order to ensure they are better prepared to deliver EOLC when they enter the CLE.

### **Limitations to the meta-ethnography**

There are several limitations to this meta-ethnography. Sample characteristics were only partially available so it was unclear if the student's age, gender, previous personal or professional experiences influenced EOLC. In addition, the curriculum for two American studies comprised a four year baccalaureate with clinical placements in the second, third and fourth year (3,6). In contrast, in the UK curriculum clinical placements are distributed throughout the three year programme. Although this limited comparison, findings from these studies produced valuable insights into P-RNs' experiences and so were included in the meta-ethnography.

There are a number of methodological limitations. The existing literature may not have identified all the salient factors that influence P-RN's experiences. Students may have self-selected into the studies if they had a specific interest or problematic experiences, resulting in an overemphasis upon extreme scenarios. Nevertheless, these gave an important insight into P-RNs' experiences. Despite these limitations these findings are important as they reveal commonalities that transcend context revealing insights into P-RN's experiences of EOLC.

### **Gaps in knowledge**

RNs are expected to deliver compassionate EOLC to patients and their relatives yet despite the End-of-life-Care Strategy (DH 2008), examples of less than optimal care continue to be reported (DH 2012a, 2013). There are no curriculum guidelines for EOLC for P-RNs in England and subsequently a consensus is lacking regarding end-of-life education among undergraduate programmes (Dickenson et al 2008). This inconsistency is thought to contribute to the variable care received by patients and their relatives (DH 2013). Results

from this meta-ethnography reveals little is known about the factors that enhance and inhibit P-RNs learning the skills, knowledge and attitudes to provide high quality EOLC.

In Chapter 2, the focused review in EOLC education revealed an increase in knowledge and positive changes in P-RNs' attitudes towards the dying and their relatives following a combination of EOL theory, cinemeducation, simulation and experiential learning (Degner & Gow 1988, Arber 2001, Mallory 2003, Kwekkeboom et al 2005, 2006 Barrere et al 2008, Dobbins 2011, Weissman 2011, Fluharty et al 2012, Moreland et al 2012, Twigg & Lynn 2012). Although participants' attitudes, knowledge and behaviour scores were higher amongst those who experienced teaching methods that combined theory with experiential learning, learning in the CLE was not explored. Hence it is difficult to explain with certainty why these educational initiatives increased P-RNs' knowledge and attitudes. Additional uncertainties include understanding how P-RNs apply their knowledge and skills to EOLC and how they learn the skills of communicating sensitively with patients and relatives. Thus it is clear that more information is required about the factors that inhibit and enhance learning EOLC in the HEI

The findings from the meta-ethnography were synthesised into a conceptual map of pre-registration nurses' experiences of EOLC (Figure 3.2). This reveals the emotional impact upon P-RNs due to performing last offices, their past experiences and difficult communications with patients and relatives (Johnson 1994, Kiger 1994, Beck 1997, Loftus, 1998, Cooper & Barnett 2005, Allchin 2006, Terry & Carroll 2008, Parry 2011). It also identified that EOLC can be a rewarding experience when a P-RN is supported by a RN and conversely unrewarding/distressing when they are not supported. Therefore, it is evident that a substantial component of learning occurs in the CLE and although the studies synthesised reveal P-RNs experiences, they do not show how they learn to manage their emotions. In addition, it is unknown which components of working with an RN enhance and inhibit their learning to communicate in a sensitive manner. Furthermore, little is known about how previous personal and professional experiences contribute to learning EOLC. These gaps in the evidence suggest further research is required to answer the question 'What

factors in the Clinical Learning Environment enhance pre-registration nurses learning end-of-life-care?'

## **Summary**

The nursing profession aims to ensure that P-RNs learn to provide compassionate EOLC according to an individual's needs. In order to determine how to improve educational support, it is important to discover factors that enhance and inhibit their learning in the HEI and CLE. My research proposes to address this through an exploratory focus group investigation, to reveal P-RNs perspectives upon how learning EOLC could be enhanced in the HEI and CLE. The following chapter will explore the research design.

## **Chapter 4 Method**

### **Introduction**

While there is a body of work exploring P-RNs' experiences of end-of-life-care and changes in attitudes following educational input, there has been little investigation into their perceptions of factors that enhance and inhibit their learning EOLC. This chapter presents the aims and objectives of the study, explains the research methodology and the methods in more detail including the sample selection, process of data collection and how the data were analysed. The ethical considerations and the steps taken to increase the rigour and credibility of the findings are also discussed.

### **Research aim and objectives**

#### Aim:

To explore undergraduate pre-registration nurses' perceptions of how learning end-of-life-care could be enhanced in the Higher Education Institute (HEI) and Clinical Learning Environments (CLE).

#### Objectives:

To examine P-RNs' perceptions of the:

- preparation received in the Higher Education Institute to provide end-of-life-care
- educational support received in the Clinical Learning Environment when providing end-of-life-care
- strategies used by P-RNs to enhance learning end-of-life-care

### **Research design: Focus group methodology**

The aims and objectives required methods that enable participants to express their perceptions of the preparation and support they receive to learn EOLC in their educational programme. This required a qualitative approach to yield descriptive data from the participants themselves. Focus group methodology was the best method to adopt for my investigation. This section will explore focus group methodology and the rationale for their use in this study.

The qualitative paradigm accepts there are multiple views of reality and one of the strengths of focus groups is that individuals share their diverse perspectives (Brotherson 1994, Vaughn et al 1996). In addition both the qualitative paradigm

and focus group methodology acknowledge that data are formulated by the interaction between the researcher and participant and also between participants (Brotherson 1994). Finally, in the qualitative tradition, the notion of truth is influenced by an individual's perspective and context, so the findings are not generalised to the wider population (Ritchie et al 2014). Focus group methodology aims to gain a greater understanding of beliefs, attitudes and experiences from multiple points of view in the context of the discussion (Brotherson 1994). Therefore focus group methodology with its emphasis upon data emerging from group dynamics and interaction was applicable to explore P-RNs' perceptions of factors that enhance learning EOLC. In Calder's (1977) typology, focus group knowledge is classified as clinical, phenomenological or exploratory. Previous phenomenological focus group studies explored P-RNs' lived experiences of caring for the dying, but these lacked an in-depth exploration of factors that may influence learning in the HEI and CLE (Johnson 1994, Terry & Carroll 2008, Parry 2011). My investigation was exploratory because it sought to understand how learning EOLC can be enhanced.

Focus groups were developed in the social sciences by Merton and Kendall and have been applied in market and academic research (Merton et al 1990).

Focus group methodology is:

'a group discussion exploring a specific set of issues. The group is focused in that it involves some kind of collective activity...by the explicit use of group interaction to generate data' (Barbour & Kitzinger 1999 p4).

In this definition the justification for focus groups is to elicit rich data through the discussion between participants. This interaction reveals the participants' authentic voice by their language, and how they conceptualised their concerns, in a fully articulated account (Basch 1987, Wilson 1997). Krueger and Casey (2009) expand upon this explaining that the permissive environment empowers participants to lead the discussion 'taking the research to new and often unexpected directions' (p4). This is in contrast to interviews, questionnaires, Delphi and nominal groups which are led by the researcher's agenda and therefore may not reveal the same range of perspectives as focus group discussions (Merton et al 1990, Morgan 1997, Barbour & Kitzinger 1999, Wilkinson 1998). A unique feature of focus groups is the opportunity to observe the process of participants sharing and comparing their opinions and

experiences to co-construct their meanings and understandings about the topic (Wilkinson 1998, Liamputtong 2004, Morgan 2012). Consequently, the interaction aims to produce a range of similar and differing opinions about the issue being discussed (Merton et al 1990). As a result focus group methodology produces two types of data: content-orientated as well as the interactive conversation-orientated group dynamic 'how it was said' (Macnaughten & Myers 2004, Morgan 2010). Content-orientated focus groups explore the substantive data produced by the interaction within the group to reveal commonalities and differences about the topic under discussion. The analysis is exploratory with the findings drawn together into themes or categories. Therefore the interaction creates the data but is not considered the data (Macnaughten & Myers 2004, Morgan 2010). In conversation-orientated research the interaction is analysed as data. Patterns are examined that indicate the way people take on roles to set up conversations, deal with disagreement and continue the conversation through taking turns to talk (Macnaughten & Myers 2004, Morgan 2010). My investigation aimed to investigate how learning could be enhanced, from P-RNs' opinions and therefore a content-orientated focus group was applicable.

#### Rationale for focus group methodology

Having defined focus group methodology it is necessary to explore the advantages of its use within this investigation in relation to the researcher-participant relationship, sensitive nature of EOLC and participants' learning. The choice of data collection method was an important consideration given the relationship between the researcher, with the dual role of lecturer and the P-RN as participant. Both interviews and focus groups enable participants' to express their views about learning EOLC. However, interviews were considered disadvantageous because of the hierarchical relationship between the researcher and participants. Bradbury-Jones & Alcock (2010a,b) warn that the hierarchical relationship between the lecturer as researcher and participants who are P-RNs could result in participants becoming defensive. During interviews this may inhibit contributions by P-RNs through their supplying answers they may think the researcher wants to hear, or using theoretical responses such as 'I would....' (Silverman 2007). This would impede understanding of the factors that P-RNs perceive to enhance learning EOLC.

An advantage of focus groups is that group interactions make the power relationship between researcher and participants more egalitarian. This is partly achieved by 'safety in numbers,' as there are more participants than researchers. In addition focus groups are less structured than interviews, which empowers participants to drive the conversation into areas they perceive as important, while building upon each other's views and reconsidering their own understandings. This more natural flow of discussion reveals participants' idioms, terminology and their views about the topic (Byers & Wilcox 1991, Kitzinger 1994, Catterall & MacLaran 1997, Morgan 1997, Barbour & Kitzinger 1999).

There is limited evidence comparing the effectiveness of focus groups with interviews. Fern's (1982) market research study found the quality and quantity of topics produced was statistically significantly higher among interviews compared to focus groups. However, it has not been proven that these findings are applicable to a healthcare topic. Wilson's (1997) Lifestyle Options study asked the same questions of men and women during either an interview or focus group. During the interview the researcher felt constrained by the questions and the interviewees' answers were limited. In contrast, focus group participants facilitated the conversation by challenging each other's responses in ways the researcher had not considered which enhanced the richness of the data and shifted the balance of power from the researcher to the participants. Therefore, despite evidence that a lower number of topics were produced (Fern 1982), focus group methodology with its focus upon participants driving the content of the conversation, was an appropriate method to empower P-RNs to share their perceptions in my investigation.

For topics, such as EOLC, which are likely to evoke emotional responses, it has been assumed that individuals will not want to share experiences in a group discussion (Jayasekare 2012). However, focus group participants have been found to encourage shyer members to contribute by sharing their similar experiences about bereavement (Morgan 1989), cancer (Wilkinson & Kitzinger 2000), and perinatal loss (Cote-Arsenault & Morrison-Beedy 2001). In addition, P-RN's have shared their first experiences of EOLC, challenges of communicating with patients and relatives, performance of last offices and flashbacks to their own bereavements within focus group discussions (Johnson



1994, Cooper & Barnett 2005, Terry & Carroll 2008, Parry 2011). Importantly these studies revealed the range of experiences and opinions that is the objective of focus group methodology (Merton et al 1990). Together this evidence suggests that focus groups are suitable for facilitating P-RNs' discussion of learning EOLC.

A final advantage of focus group methodology was that throughout the BSc programme P-RNs undertook problem based learning (PBL) in groups to solve healthcare problems. Hmelo-Silver (2004) explains that the strength of PBL is that students are at the centre of learning, which stimulates them to work together to identify their learning needs and prior knowledge to co-create a solution to the problem. Wibeck et al's (2007) study of Swedish civil servants identified commonalities between the processes of PBL and focus group interaction. Similar to PBL, focus group participants worked together by sharing and comparing their experiences and opinions to co-construct their knowledge (Wibeck et al 2007). The similarities with the learning process during PBL and co-construction of knowledge within a focus group may have facilitated P-RNs contributions in previous studies (Johnson 1994, Cooper & Barnett 2005, Terry & Carroll 2008, Parry 2011). This evidence suggests that focus groups offer an effective way to enable P-RNs to co-construct their understanding of factors that enhance learning EOLC.

In summary, focus group methodology was selected as the most appropriate method for my investigation since it empowers participants to lead the conversation into areas the researcher had not considered, to compare their experiences of learning, while reducing the power hierarchy between the researcher and participants. This facilitates a deeper insight into P-RN's experiences by revealing factors that enhance their learning EOLC in HEI and CLE. Focus group methodology emphasises participants' interaction as the data source, however Agar & MacDonald (1995) and Krueger and Casey (2009) argue that it cannot be assumed that just getting a group of people together means they will talk about their needs and concerns. Therefore, the following section explores strategies used to promote group interaction with consideration to sample recruitment, data collection and ethical issues. Finally the process of data analysis and strategies used to promote rigour are presented.

## **Sample Recruitment**

### Sample selection: homogeneous or heterogeneous

In relation to focus groups, sample selection is the most important influence upon the discussion (Morgan 2012). There is no clear consensus about whether a focus group sample should be homogeneous or heterogeneous. Exogenous homogeneity describes participants with similar backgrounds and demographic characteristics such as age, gender, ethnicity, social class or religion (Corfman 1995). In comparison, issue homogeneity is concerned with participants who have similar experiences (Corfman 1995). There is no consensus on the degree of homogeneity that should be achieved within a focus group. It has been argued that when a group has lower exogenous homogeneity due to varying ethnicity, religious beliefs and social backgrounds it is difficult to promote discussion, whereas, a higher exogenous homogenous group may improve interaction and encourage self-disclosure (Welch 1985, Carey & Smith 1994, Corfman 1995). Alternatively, people with varying ages, or social backgrounds may report a range of contrasting perspectives (Krueger 1998, Kitzinger 1994, Wilson 1997).

For Morgan (2012) issue homogeneity is more important than exogenous homogeneity when discussing sensitive topics such as alcoholism, sexual practices or death, as participants may only feel comfortable discussing with those with similar experiences. For instance, Morgan's (1989) study of social support following bereavement ensured high issue homogeneity as participants were bereaved widows, and low exogenous homogeneity, as participants were from mixed social classes, ages and religions. Morgan (1989) reported the various backgrounds had little impact, because participants' bereavement was the fundamental similarity. Corfman's (1995) focus group study into the sensitive topic of diet and weight loss among 99 non-nursing students in a HEI also concluded that exogenous homogeneity did not impact upon the discussion. Rather, interest in the topic and the moderator's ability to create an encouraging environment were more influential upon participants' willingness to contribute. More recently, Greenwood et al (2014) explored the influence of ethnicity on focus group discussions among 40 carers of family members who had had a stroke. Two focus groups were heterogeneous with participants from White British, Asian, Black African and Black Caribbean backgrounds. Five groups were ethnically homogeneous, with only White British, Asian, or Black

African and Caribbean participants. Greenwood et al (2014) concluded that participants shared and compared their experiences about stroke irrespective of ethnicity. When the topic changed to cultural difference in healthcare delivery the ethnically homogenous groups appeared more comfortable discussing the issues, due to the similar backgrounds. In light of the evidence outlined above is samples in my study were selected to ensure there was issue homogeneity.

### Sampling techniques

A purposeful sample approach was used to recruit P-RNs with experience of EOLC into the study. Up to 50 participants were to be recruited from a cohort of 110 third (final) year students on the BSc Nursing Studies with Registration (Adult) programme, (i.e. pre-registration nurses P-RNs) at one Faculty of Nursing and Midwifery in London. This programme was chosen as potential participants had completed compulsory EOLC theory in lectures, problem based learning tutorial groups and undertaken clinical placements. Therefore, they would be able to explore their perceptions of how learning EOLC could be enhanced in HEI and CLE. Focus group composition was managed to ensure high issue homogeneity, therefore all third/final year P-RNs who had shared the same lectures in the same HEI were invited. Twelve participants were recruited into three focus groups: Focus group A (FGA n=5); Focus group B (FGB n=5); and Focus group C (FGC n=2). Participants in each focus group were demographically diverse (low exogenous homogeneity) in terms of gender, age range and marital status, so as to capture a range of perceptions (Morgan 1997, Ritchie et al 2014). It was planned that one focus group would be high in issue homogeneity and highly heterogeneous including only male students to explore issues related to gender differences, however only one male was recruited. These are discussed in Chapter 5, Participants' characteristics and presented in Tables 5.1, 5.2, 5.3, 5.4.

### Exclusion criteria

Pre-registration nurses were excluded if they were enrolled on the following programmes:

- BSc Nursing Studies Children's Nursing as the focus was learning how to care for adults who were dying
- BSc Nursing Studies Mental Health as deaths occur rarely

- Diploma in Higher Education because diploma training is being phased out (NMC 2010b)

BSc Nursing Studies (Adult) nurses were excluded if they:

- reported no experience of end-of-life-care as they would not be able to discuss examples of learning in clinical practice
- had a family member who was seriously ill at the time of data collection as they might have found the discussions distressing

#### Recruitment: maximising response and reducing coercion

Permission to undertake the investigation and access the P-RNs was granted by The Head of the Faculty of Nursing & Midwifery (Appendix 3) and the King's College London Psychiatry, Nursing and Midwifery Research Ethics Sub-Committee Ref: PNM/10/11-150 (Appendix 4).

The aim of recruitment was to maximise the sample without coercion due to the power relationship between the researcher/lecturer and P-RNs (Bradbury-Jones & Alcock 2010b). Parry (2011) reported low recruitment as participants forgot to attend focus groups when in clinical practice. Therefore, the BSc Nursing Studies (Adult) Programme Leader identified a teaching session in the Research Methods module when the researcher could meet the target cohort to explain the aims. In addition as participants were in the HEI they were potentially available for data collection. Participants opted into this study following an e-mail invitation sent by the Departmental Secretary that contained the researcher's contact details (Appendix 5) and Participant Information Sheet (Appendix 6). Interested students contacted the researcher and were sent a Consent Form (Appendix 7). In addition a Background Questionnaire (Appendix 8) was sent to participants for them to complete and return to the researcher. Following review of the Background Questionnaire ineligible individuals were emailed and thanked for completing the form and an explanation given as to why they were not invited to join the focus group interview. Eligible participants were emailed the venue date and time for a focus group. Correspondence was signed as a researcher with a unique email address to reinforce the researcher rather than academic role (Bradbury-Jones & Alcock 2010b). To reduce coercion, the Departmental Secretary emailed reminders to non-responders three weeks after the first email.

## **Data collection**

### Demographic data

Demographic data were collated from a Background Questionnaire (Appendix 8) to place each participant's comments within the context of age, gender and experience of caring for people who are dying before and during the BSc programme.

### Topic guide development

The topic guide was informed by the results from the meta-ethnography (Chapter 3), curriculum documents, European Guidelines for Education in Palliative Care (De Vliegner et al 2004b) and Common Core Competencies (DH 2009). A threat to an effective focus group is including too many questions or that concepts are too formal so participants are discouraged from adding their perspectives (Krueger & Casey 2009). To reduce this effect a list of six topics were selected with open questions to encourage individuals to reveal important issues (Krueger & Casey 2009), (Appendix 9). Each focus group was audio recorded, with permission and transcribed verbatim. After each focus group the data were analysed and the findings explored in subsequent groups. This enhanced rigour as it allowed reflection upon the findings, fine tuning of questions and the addition of new ones to reflect the content discussed by previous participants, such as 'learning through debrief.' If all the focus groups had been completed before analysis commenced new issues could not have been explored (Krueger & Casey 2009).

### Focus group size

There is limited empirical evidence regarding the optimal number of participants to promote a discussion. In market research Fern (1982) found larger groups of eight participants produced more topics than smaller groups of four participants. Wilson's (1997) qualitative study exploring Lifestyle Options found more spontaneity and snowballing of topics among groups of four to eight participants than those of nine to twelve. Morgan (1997) suggests six to ten participants, while Krueger and Casey (2009) consider smaller groups of three to six permit each person to contribute. David and Sutton (2004) explained that the more knowledgeable or motivated the group members, the smaller the group needs to be to generate discussion (David & Sutton 2004). In my investigation there were twelve recruits. Focus groups of between three to five participants were

selected to allow each person the opportunity to share their perceptions and produce rich data, and to avoid the tendency for fragmentation and inhibition of the discussion seen in larger groups (Wilson 1997, Krueger & Casey 2009). Focus Group A (FGA) and Focus Group B (FGB) both contained five participants. If only two participants attended a paired interview would be offered, or a one-to-one interview if only one attended, using the same topic guide to promote parity (Finch & Lewis 2003). Two participants attended instead of the expected three for Focus Group C, and agreed to a paired interview. Focus groups took place between October and December 2011. These are presented in Chapter 5 Participants' characteristic and Tables 5.1, 5.2, 5.3 and 5.4.

Sample recruitment was slow during the three months the P-RNs were available in HEI. There is a lack of empirical evidence for the optimal number of focus groups. Calder (1977) in marketing research and Zeller (1993) in social science research both claim that more than three to five groups with similar members rarely generate new data. The number of groups is also influenced by recruitment as in Howard et al's (1989) investigation which was limited to one focus group due to difficulty finding a mutually convenient time. As there is no consistent advice David & Sutton's (2004) recommendation for focus group recruitment to be guided by the extent of data saturation was to be followed. However, in my investigation the number of focus groups was limited to three by the number of recruits and therefore it is unknown if more focus groups would have contributed another perspective.

In terms of focus group composition, some researchers believe pre-existing groups of acquaintances, friends, work colleagues, clubs or family members, encourage the production of more fully articulated accounts than strangers. A quantitative market research investigation by Fern (1982) found the number and quality of topics was not statistically significant between groups of acquaintances or strangers, suggesting there is little difference. Several qualitative studies reported similar findings of acquaintances in focus groups exploring HIV (Kitzinger 1994), mental health (Powell et al 1996), breast cancer (Wilkinson 1998) and stroke (Greenwood et al 2014). These acquaintances from pre-existing groups offered a supportive environment conducive to open discussion which produced credible findings through participants' recollection of

common experiences and half-forgotten memories as well as their willingness to challenge contradictions (Kitzinger 1994, Powell et al 1996, Wilkinson 1998, Greenwood et al 2014).

However, Wilson (1997), Krueger and Casey (2009) warn that pre-existing groups have formal and informal hierarchies that may inhibit discussion and create participant bias. Two strategies can be used to reduce participant bias: by creating sub-groups to compare the findings; and randomisation of the sample into different groups to separate acquaintances and promote discussion as in Johnson's (1994) study into P-RNs experiences of EOLC. However, it is unclear if a group of acquaintances would have inhibited or promoted the discussion. This evidence suggests there is a tension between selecting acquaintances or strangers to encourage a diverse discussion. Hence, in my investigation the potential for revealing important findings against possible participant bias was weighed and it was decided to include both acquaintances and strangers in the focus groups to promote diversity during the interaction.

#### Moderator's role

The role of the moderator is central to the success of a focus group discussion. Participants face two problems when interacting within a group: firstly how to establish common ground for communication and secondly how to contribute and expand that discussion (Hydén and Búllow 2003). For some people self-disclosure comes easier and for others it takes courage. People are more likely to share their opinions when the moderator makes them feel comfortable and respected (Corfman 1995). Thus participants rely on the moderator to guide them towards what is expected from them during the interaction (Hydén and Búllow 2003).

The researcher (SH) was the moderator and was a lecturer/nurse who had cared for the dying for over 30 years and had over 15 years' experience facilitating group discussions and managing dominant personalities in group discussions. As an insider in the HEI this contributed to data validity by having the insight to ask pertinent questions. An external moderator may lack knowledge of pertinent issues (Krueger & Casey 2009). However, as there was a risk of a power hierarchy inhibiting the discussion, the moderation style was considered. Two styles have emerged to promote discussion. Firstly, Morgan & Spanish (1994) utilised a minimal role with participants sitting in a circle and

researchers clarifying the topic with an opening question then sitting at another table to observe the interaction. However a major drawback is that it is difficult to encourage shy members to contribute and manage dominant personalities. Secondly, is an interactive style where the moderator sits with the participants. This method was selected as it has the advantage of being able to encourage contributions from more reticent participants, facilitate a range of responses and manage dominant participants (Kitzinger 1994, Wilson 1997, Krueger & Casey 2009). However, a moderator can bias data by imposing their beliefs and values and using leading questions. Therefore, the moderator critically reflected upon personal experiences, roles and preconceptions before and after each focus group and used strategies to reduce potential bias due to an imbalance in power. This included not sharing opinions and using silence to allow the participants time to think and contribute to the discussion (Krueger and Casey 2009). Text box 4.1 provides an example of reflexivity/reflection.

#### Text Box 4.1 Reflexivity during a focus group

##### **Reflection 22/11/2011 Focus group B (excerpt)**

During FGB I reflected upon how to reply when a student revealed she did not know how to respond to a challenging question from a patient. Instinctively I wanted to facilitate her learning, yet chose to purposefully detached my-self from joining the conversation and by remaining silent allowed the group to respond. Consequently other participants started to share their learning experiences and gave advice. Thus using silence to stay in the role of moderator allowed the group to co-construct the challenges of how to respond to challenging conversations.

A relaxed atmosphere was created by welcoming each participant, providing refreshments and arranging the chairs in a circle to promote a non-hierarchical discussion. The discussion commenced with the moderator explaining the aim of the investigation, how to maintain confidentiality and the need to respect opinions and contributions of all group members during the discussion. An opening statement explained there were no right or wrong answers and that the aim was to understand their experiences of learning to care for the dying. Open questions were used to encourage participants to share their experiences. As the discussion progressed there was less reliance on these predetermined questions by the moderator as the participants led the discussion. The moderator listened to the conversation and valued all contributions. The moderator asked questions to probe and develop understanding. If there was



not an immediate response the researcher/moderator was silent for a count of 10 to allow the participants time to respond (Krueger & Casey 2009). If a participant had not contributed to a topic they were asked if they had similar or different experiences. Conversely if participants' body language was closed the topic was not pursued further. This occurred when Isabelle (pseudonym) identified that she had cared for her mother, however as the conversation progressed and other members shared their personal experiences, Isabelle's body language became more open and she shared her experiences with the group.

In focus groups dominant individuals can intimidate or silence a member or topic, which may limit the range of responses and create a false consensus or group think (Morgan 1997). McLafferty (2004) described an enthusiastic P-RN who dominated the start of a focus group discussion about attitudes toward older people. However, once the moderator valued the participant's contributions and widened the discussion to others the group all shared their diverse experiences. Therefore, this approach was adopted in this investigation.

In my study there were examples of participants working together and highlighting inconsistencies between participants' experiences which led to insightful conversations about conflicting advice from mentors in the CLE and forgotten theoretical sessions on EOLC in HEI. All three groups collaborated and talked spontaneously developing and reframing views. The interaction within each group was different. FGA and FGB included five participants who had clinical placements in a variety of NHS Trusts, in contrast FGC contained two close friends from the same NHS Trust. Participants in FGC explored their shared clinical experiences, personal bereavement and were mutually supportive. Subsequent to each focus group participants described the discussions as cathartic, helping them to explore their roles caring for the dying, suggesting that they found the focus group experience contributed to their learning.

To close the discussion three types of questions were used to enable participants to reflect on previous comments and to assist with the analysis (Krueger & Casey 2009), (Appendix 9). Firstly, to ensure critical aspects had not been overlooked the moderator asked the 'insurance' question, '*Do you think there is anything that we have missed that we should talk about?*'

(Krueger & Casey 2009 p46). This led to participants' in FGB discussing challenging conversations. Secondly, the 'all things considered' question *'Please reflect upon the discussion and identify which point is the most important to you?'* (Krueger & Casey 2009 p46). This assisted with analysis as topics may be talked about frequently in a group but may not be the most important. This question assigns weight to the factors that enhanced or inhibited learning when there were conflicting perspectives (Krueger & Casey 2009). Finally, the moderator provided a verbal summary of the discussion points and asked the participants *'If this was an accurate summary?'* (Krueger & Casey 2009 p46). This provided feedback about the moderator's interpretation of the discussion which promoted the accuracy and credibility of the analysis (Krueger & Casey 2009).

An Assistant Moderator attended each focus group. She was an experienced lecturer and researcher with the necessary interpersonal skills to support distressed P-RNs. Her responsibilities were to manage the audio recording, be attentive to background sounds, record field notes about discussion points/body language and manage interruptions. She also provided an invaluable contribution by debriefing with the Researcher/Moderator to discuss overall impressions, quotations, key ideas and insights.

### **Ethical issues**

Learning how to care for the dying is a sensitive topic as it may reveal distressing personal and professional experiences. In addition the dual roles of researcher/lecturer may influence the relationship with the participant leading to coercion or fear of being scrutinised. Ethical issues in educational research identified by Lee and Renzetti (1993), Dickson-Swift et al (2008a), Cohen et al (2011) and the Framework for Ethical Research Practice for Nursing Students (Bradbury-Jones & Alcock 2010b) were reviewed and strategies included to safeguard P-RNs rights during data collection and writing the research report as discussed below. Permission to access students was obtained from the Head of the Faculty of Nursing and Midwifery (Appendix 3) and ethical approval was sought and obtained from the King's College London Psychiatry, Nursing and Midwifery Research Ethics Sub-Committee Ref: PNM/10/11-150 (Appendix 4).

### Researcher/lecturer and participant relationship

The Framework for Ethical Research for Nursing Students (Bradbury-Jones & Alcock 2010b) advocates examining the relationship between P-RNs as participants and the dual role of researcher/lecturer. This relationship may result in P-RNs feeling inferior, being afraid of giving the wrong answer or being defensive, all of which might inhibit recruitment or sharing of their perceptions (Bradbury-Jones & Alcock 2010b). Therefore it was important to understand the nature of this relationship by reflecting upon the complexity of the dual roles of researcher/lecturer and creating strategies to minimise this conflict. In anticipation of the investigation in 2011, critical reflection was performed with the Departmental Manager in 2008 and consequently it was planned that I would not teach the potential participants during their programme. However, contact could not be completely eradicated and six were allocated to a clinical area where I was the link lecturer. They subsequently chose not to participate in the study.

### Informed consent, the right to withdraw, autonomy and confidentiality

Potential participants' autonomy was promoted so they could make an informed choice regarding participation by giving them a Participant Information Sheet (Appendix 6) and an opportunity to telephone or email the researcher with any questions (RCN 2009). Participants may be afraid of potential sanctions or stigmatisation due to their comments or not participating (Bradbury-Jones & Alcock 2010b, Cohen et al 2011). Therefore, it was made clear that P-RNs education would not be affected by either choosing or not choosing to participate. Before each focus group participants were reminded that whilst they had the right to withdraw at any time, any data collected during the focus group discussion could not be withdrawn, as it was part of a group discussion. The participants were informed that the HEI did not have access to the participant's individual data and that their opinions were valued and confidential.

Confidentiality was maintained according to the Data Protection Act 2003 (HM Government 2003) and pseudonyms used instead of the names of participants, Trusts and HEI during data analysis and written reports. Personal information about ages was presented as younger and older groups. To further protect confidentiality participants' personal experiences of EOLC before the BSc programme were grouped into three clusters: direct care, indirect care and no

experience which provided anonymity. An assigned number and pseudonym were written on each audio recording, transcription and Background Questionnaire. Participants' personal data were stored on an encrypted USB key and written transcripts were stored in separate locked filing cabinets. A copy of the code which links participants' names to the research data was stored in separate locked filing cabinet, and audio recordings deleted after data analysis. Transcripts were accessed by the researcher and research supervisors. None of the participants withdrew after signing the consent form.

#### Potential harm and managing participants' distress

The researcher reflected upon the possibility that some of the discussion might raise strong emotions and recollections of distressing experiences (Lee & Renzetti 1993, Dickson-Swift et al 2008b). Therefore, the following protocol was devised to recognise distress and handle it with sensitivity (RCN 2009, Bradbury-Jones & Alcock 2010b). Distressed participants were given the option to continue within the focus group or leave with the Assistant Moderator for debriefing support in another room. The participant could then re-join the group or leave. After each focus group all participants were given the opportunity to debrief and provided with follow-up helpline numbers including the Royal College of Nursing (RCN 2007) and University Student Counselling services.

#### Protocol to manage disclosures of criminal activity or misconduct

Although the chances were small, this investigation could have uncovered professional misconduct in healthcare (Lee & Renzetti 1993). As a RN guided by The NMC Code (2008c) there was a duty of care to patients so a protocol was devised to report concerns of misconduct following the Raising and Escalating Concerns guidance to the relevant managers in the clinical area and HEI (NMC 2010c). Furthermore, it was emphasised in the Participant Information Sheet and at the start of each focus group interview that the aim was not to uncover examples of misconduct and any revealed would be reported. No examples of misconduct were discussed during data collection.

#### Risk to the organisation and lecturer

The HEI and its lecturers' beliefs may be challenged when participants' comment on lectures and support they receive (Lee & Renzetti 1993, Dickson-Swift et al 2008b). A discussion with relevant lecturers was undertaken before

the investigation to explore their perceptions. They enthusiastically welcomed the opportunity to discover P-RNs' opinions on areas to develop for education of EOLC. Feedback to lecturers after data analysis included positive aspects and areas for development to reduce the threat to lecturers. As the researcher/lecturer I reflected upon the impact of participants' criticism upon myself (Appendix 10). It was decided to value each comment and debrief with the assistant moderator after each focus group.

## **Data analysis**

### Management of transcripts

Participants' characteristics from the Background Questionnaire were tabulated in Microsoft Excel and each focus group interview was transcribed verbatim using Microsoft Word. Any errors were corrected, as even minimal mistakes had the potential to alter the analysis and therefore the interpretation. To compare participants' characteristics to their comments and explore the flow of the conversation, participants were allocated a code related to the seating plan (Krueger & Casey 2009). The computer assisted qualitative data analysis system NVivo 10 was used initially to organise and assist data analysis and perform open coding (QRS 2011). This was chosen as Gibbs (2002) and Bringer et al (2004, 2006) found it assisted with open coding from focus group data and helped to move from describing to conceptual ordering by exploring preliminary relationships. As the data analysis progressed Microsoft Word was used to record memos and group similar data together.

This focus group investigation used content-orientated data analysis which can be categorised as either 'whole group' or 'participant based.' The analytical advantages and disadvantages were weighed against the aims and objectives of the investigation. 'Whole group' analysis treats the data without delineating individual contributions so that data are summarised and indexed as a group. This has the disadvantage of not being able to explore linkages between individual's age, gender or prior experiences in EOLC that may have influenced their learning. In contrast during 'participant based' analysis, the contributions were separately analysed within the context of the discussion, so each individuals data is explored (Spencer et al 2014). This method was selected as it has the advantage of permitting an exploration of linkages between individual's age, prior experience and their learning EOLC. A further advantage

was an examination of the similarities and differences among participants in the groups (Merton et al 1990, Krueger & Casey 2009). Differences were difficult to compare when reading the whole transcript so each participant's contribution was separated from the others to create 12 transcripts which were loaded as participants' data in NVivo 10. This enhanced the analysis as it allowed individual's stories to be pieced together to explore internal consistency by tracking changes (Krueger & Casey 2009). These strategies allowed a systematic exploration of participants' characteristics during the analytical technique of open coding.

#### Overview of constant comparison data analysis

There is no one specific method to analyse focus group data (Merton et al 1990, Krueger & Casey 2009, Morgan 2012, 2015). Strauss & Corbin's (1998) method of constant comparison data analysis was selected as it provides a framework to examine the context, actions and consequences that enhance and inhibit learning. In addition, constant comparison ensured a systematic analysis of the data in clearly defined stages (Glaser & Strauss 1967, Strauss & Corbin 1998). Studies by Kitzinger (1994), Donovan (1995) and Bringer et al (2006) found constant comparison promoted credibility when analysing focus group data by seeking similarities and contrary cases and incorporating them into the data. Constant comparison is defined as:

'a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with category, category with category and category with concept. Comparison constitutes each stage of the analytical development' (Charmaz 2006, p607).

The constant comparative method consists of comparing incidents from the data; integrating themes and their properties; delimiting the theory and writing theory (Glaser & Strauss 1967). The aim is to 'make analytical sense of the material which may challenge taken for granted understandings' (Charmaz 2006 p54). Newly gathered data are given a code which defines a participants view, process, action or belief (Charmaz 2006). Codes are compared with previously collected data and become either new categories or join existing ones (Bowen 2006). Therefore data are compared for similarities and differences between statements from the same participant and between participants. Sequential comparisons are also made by comparing earlier and

later data at different times and places to reveal a process of development. Constant comparison is influenced by the researcher's perspective by asking 'What does this remind me of?' and 'How is this different to my experiences?' (Ryan & Burnard 2003 p91). However this may bias the analysis. Therefore, Charmaz (2006) advises acknowledging personal preconceptions as one of many perspectives, consciously seeing the world through the participant's eyes and 'looking for how they understand their situation before you judge their attitudes through your own assumptions' (p54). The researcher does not dismiss their ideas or intuitions; instead they become data to compare to participant's data (Charmaz 2006). Categories emerge from patterns and interrelationships which ultimately form the core category of emerging theory. The process includes the constant search for falsifying evidence that would refute emerging theory (Glaser & Strauss 1967). In this regard the constant comparative method serves to test concepts and themes with a view to producing theory grounded in the data (Bowen 2008).

Strauss & Corbin's (1998) constant comparison uses open, axial and selective coding. Written memos record analysis of codes and merging categories at each of these stages to facilitate cross-referencing codes and categories and act as an audit trail of the decisions made (Strauss & Corbin 1998). Open, axial and selective coding will be briefly explained and then explored in more depth related to my investigation.

Open coding is defined as 'identifying the concepts, properties and dimensions in the data' (Strauss & Corbin 1998 p101). This descriptive analytical process consists of examining sections of text made up of individual words, phrases and sentences. Strauss & Corbin (1998) explain 'this fractures the data and allows one to identify some categories, their properties and dimensional locations' (Strauss & Corbin 1998 p97). Properties are categories that contain a range of codes along a continuum called dimensions. For instance, the property 'Previous experience in EOLC' has the range of codes '*Direct EOLC as a relative;*' '*Direct EOLC as HCA/volunteer;*' '*Indirect EOLC through experience of a relative or friends distress when grandparents died;*' and '*No previous experience of EOLC.*'

Conceptual ordering occurs through axial coding, which puts the fractured open codes data back together in a new way by 'creating a category as an axis

around which the analyst delineates relationships and specifies the dimension of this category' (Charmaz 2006 p186). Each category is explored and explained through what Strauss and Corbin (1998) call a paradigm. This is a framework for exploring the context, causes of the phenomenon, actions that contribute to the phenomenon and its consequences (Strauss & Corbin 1998). Finally, selective coding is the process of analysing codes and memos created during open and axial coding to identify the core category that systematically relates to all categories (Strauss & Corbin 1998). These three types of coding are interconnected throughout data analysis.

Theoretical sensitivity is recorded in memos. These refer to insights into the meaning of the data and conceptualising what is and is not important and which questions to ask of the data (Strauss & Corbin 1998). During open coding it is being aware of words or phrases in the data that suggest the phenomenon. During axial and selective coding this is extended to comparing findings to personal experiences and the literature. Thus emergent findings are compared to the literature. This is in contrast to quantitative research which fits the data to preconceived ideas and theories (Strauss & Corbin 1998, Charmaz 2006). Analysis stops when 'theoretical saturation' is achieved and where no new categories emerge, although this may be limited by the sample size and characteristics and so might not be reached (Strauss & Corbin 1998).

The process of data analysis using constant comparison techniques will be explored in relation to the development of the category 'Learning to communicate with the dying and their relatives.'

#### Open coding and open memos

Open coding of transcripts was undertaken between focus groups, which allowed time to constantly compare and contrast emerging themes and enhanced rigour by exploring new themes in subsequent group discussions (Krueger & Casey 2009). The transcript was read while listening to the tapes to become familiar with the data and gain an overview. A phrase or a word was highlighted that represented a key point, which then became an open code (Appendix 11). Each open code was compared to existing codes so that similar codes were joined together, and different ones became a new open code (Strauss & Corbin 1998). Whenever possible open code names encouraged thinking about learning. For example '*Learning to perform last offices*' was



selected over 'Last offices.' Participants' words became open codes (vivo coding), for example 'Robotic role model' was a phrase used by one of the participants. Each of the topics and questions were revisited. Some codes were expected as they derived from questions such as 'What do you find supportive in the clinical area?' Others emerged from the participants' discussions such 'Self-directed/regulated learning' in which participants described how they instigated their learning.

Each open code was read and systematically compared for similarities, differences and opposites. Open codes were grouped into complex and inclusive categories to reveal concepts (Strauss & Corbin 1998), and merged together: for instance, 'shock,' sadness,' 'grief, 'crying' were grouped into 'range of emotions.' Some categories became properties or dimensions along the continuum of those properties. For instance the category 'Learning to manage emotions' had the property 'emotional impact upon pre-registration nurses.' This included the range of dimensions, 'Overwhelmed with emotion so could not communicate;' 'learned to manage emotion to perform communication sensitively;' and 'not communicating sensitively robotic/hard.' More directive and selective focused coding occurred as decisions were made about which

#### Text Box 4.2 Open code memo example

**Open Code Memo 20/11/2011 FGB, B3 Isabelle  
Learning communication by trial and error (L627-663)  
(excerpt)**

Isabelle was washing a patient who started talking about their poor prognosis. Isabelle does not know how to respond. She does not appear to have received guidance about responding to challenging questions in HEI or CLE. Isabelle appears to learn by trial and error as she draws upon previous experiences of offering tea. This suggests that she does not appear to have the confidence or skills to sit down and listen to the patient. Getting a cup of tea was seen as being caring and allows the patient to compose themselves in Isabelle's absence. Could this be avoidance/blocking the conversation, due to not knowing how to respond? Conversely in a hospice, nurses say 'let's talk about it over a cup of tea.' Drinking tea together creates the friendly environment for a conversation. Hospice nurses use the time to get the tea to also ask other nurses not to disturb them during the conversation. Isabelle discussed this experience with RNs and FGB. A variety of responses were suggested indicating there is no consensus about how to reply. Isabelle did not find a phrase she felt she could use, suggesting that she was uncomfortable talking about this topic.

*Personal Reflection: An RN taught me to respond to these questions by active listening when I was a second year P-RN. However Isabelle appears not to have had this guidance. It is unclear why the patient spoke to a P-RN, so does this intimate environment create a bond that promotes conversation? To investigate this with the next focus group. After the data analysis look up research studies into blocking conversations and compare to findings in meta-ethnography.*

codes made most analytical sense. Codes were then moved between categories as the relationships emerged (Charmaz 2006). As a result the initial 277 open codes were collapsed into 18 categories.

Open code memos were the written record of analysis, thoughts, meaning of words, interpretations and questions, as well as directions for data collection in the next focus group (Strauss & Corbin 1998). A memo was written for each open code to identify why it was chosen and labelled with the type of memo, date written, focus group code (FGA, FGB or FGC), participant's code, pseudonym, key phrase and line in the transcript (Text Box 4.2).

#### Axial coding and axial memos

Exploring the relationship between categories and subcategories is called axial coding (Strauss & Corbin 1998). During this phase the ranges of categories were mapped, concepts defined and associations between categories found. Similar to Bringer et al (2006), this was not undertaken in NVivo10 to allow free thought and theoretical sensitivity to the meaning of the data (Strauss & Corbin 1998). This examination helped reduce assumptions and identify patterns and differences in the data. Some of these differences were immediately visible such as being allowed, or not allowed to observe conversations. Others required more exploration such as the influence of prior experiences upon learning to communicate with patients and relatives. To reduce personal bias, reflection was undertaken to compare my assumptions against the data when listening to the tapes and reading transcripts.

Understanding of the data was enhanced by exploring it through a paradigm that examined the conditions, actions and consequences (Strauss & Corbin 1998). Questions suggested by Strauss and Corbin (1998) were used to increase sensitivity and explore relationships between learning being enhanced or inhibited. Examples include asking '*What is going on here?*' '*Who is involved, RN, Doctor or P-RN?*' '*What is the RN doing?*' '*What is the P-RN doing?*' and '*Are there different consequences with different RNs, or P-RN experiences?*' Theoretical questions were used to explore the variations between data. These included '*What are the relationships between previous experiences of caring for the dying and seeking out exceptional role models/mentors?*' These questions assisted in recognising crosslinks between participant's previous experiential

and self-regulated learning, the exceptional or robotic role model and place of learning as well as subtle factors that inhibit and enhance learning.

Memos were labelled as axial memo), date written, focus group code (FGA, FGB or FGC), participant's code, pseudonym or concept being explored. The example below explores Joan learning to communicate with a distressed patient in relation to conditions, actions and consequences (Text Box 4.3).

Text Box 4.3 Axial memo: Conditions, actions and consequences

### **Axial Memo 11/12/2013 FGC, C1 Joan, Conditions, Actions and Consequences**

**Conditions** ask the questions: why? where? when?

*Causal events.* Joan found a patient crying having been told she has cancer **(challenging conversation)**.

*Intervening* factors that alter the actions. Joan was in the third/final year. She has no experience caring for the dying before the programme. Joan explained that she found talking to patients very difficult in the first year.

Joan has experience of observing nurses in A&E and care of the elderly **(exceptional role models)**. She has attended the Breaking Bad News workshop during the second year **(HEI learning)**.

*Contextual* factors. Joan is motivated to learn how to communicate with patients for when she qualifies **(self-directed/regulated learning)**. Clinical Nurse Specialist (CNS) valued Joan and encouraged her to observe the discussion **(exceptional role model)**.

#### **Actions/interactions:**

Learning was enhanced:

Joan did not block or avoid the conversation and actively listened to the patient. She appears to be applying learning from the communication workshop. She assesses the patients understanding and coordinates a referral to the CNS **(learned good communication skills, modelling role models, learning in HEI)**. Requests to observe the interaction between the CNS and patient **(self-directed/regulated learning)**.

Observing the exceptional role model demonstrating sensitive calm communication skills. Thinks about imitating this behaviour with other patients **(role modelling)**.

Learning was inhibited:

Nobody seemed to praise Joan's excellent communication skills and management of the situation **(not encouraged, or was not discussed during the interview)**.

**Consequences:** The results of the actions?

Learning enhanced:

Joan felt she had learned to use her communication skills to respond to the patient's distress **(self-efficacy)**.

Joan wants to imitate the role model by incorporating his calm manner into her communication **(role modelling)**.

This experience might be drawn upon in future conversations **(model behaviour)**.

Learning inhibited: Joan's communication skills do not seem to have been acknowledged to promote self-efficacy.

Miles and Huberman (1994), Strauss & Corbin (1998), Krueger & Casey (2009) advocate sorting findings into matrices to explore nuances in the relationships between the codes and categories by examining the frequency and extensiveness of the data. Krueger & Casey (2009) recommend exploring the data for extensiveness by exploring how many people identify a code across the groups. This promotes credibility by revealing that a code was mentioned by more than one person and across several groups. The 18 categories and their codes were transferred into a series of descriptive matrices to sort and visualise the data. Matrices explored learning communication; learning last offices; learning resuscitation; learning in expected death; learning before the programme; learning in HEI; learning from role models and participants' self-directed/regulated learning. A row was created for each code in the category and a column for each focus group participant who mentioned the code in that category. The last column represents the total so extensiveness could be compared (Table 4.1).

Table 4.1 Open codes-extensiveness

<b>CATEGORY</b> <b>LEARNING HOW TO RESPOND TO</b> <b>CHALLENGING CONVERSATIONS</b>	<b>Focus Group</b> <b>A</b>	<b>Focus Group</b> <b>B</b>	<b>Focus Group</b> <b>C</b>	<b>Total</b>
Felt unprepared for difficult questions	A1	B1,B2,B3,B5	C2	<b>6</b>
Advice about how to respond to difficult questions varied		B1,B2,B5		<b>3</b>
Do not know how to stop conversation with patient			C2	<b>1</b>
Talk about death is taboo with some RNs	A3	B4	C1	<b>3</b>
Learn by intuition, trial and error		B1,B3,B5		<b>3</b>
Do not know what to say to other patients when a patient dies	A4	B1,B2,B3,B4 B5	C2	<b>7</b>
Felt guilty when conversation went wrong	A3			<b>1</b>
Opportunity to practice under supervision	A5			<b>1</b>
RN stand-offish with patients and relatives	A4	B1,B2,B3,B4,B5	C1,C2	<b>8</b>
CNS role modelled compassionate communication	A5	B2,B3	C1	<b>4</b>
RN ward modelled compassionate communication		B3	C1,C2	<b>3</b>

These matrices helped to interrogate the data and revealed the relationships between the categories (Miles & Huberman 1994, Strauss & Corbin 1998). The researcher kept in mind that frequency of comments does not necessarily mean something mentioned only once is less meaningful as it may be a more insightful, emotional experience or an enthusiastic participant (Krueger & Casey 2009). In addition, individual's opinions may have been expressed by someone else, and others may have nodded or said yes to encourage the speaker, which

is difficult to interpret (Krueger & Casey 2009). Nevertheless, these matrices did give an indication of the more common experiences. Modifiers suggested by Krueger and Casey (2009) were applied as none, few (n=1-2), some (n=3), many (n=6-8), most (n=9-11) or all (n=12). These helped reveal the range of dominant, consistent and rarer properties that enhanced and inhibited learning (Merton et al 1990, White et al 2014). Comparisons at the property and dimension level provided a way of knowing or understanding the participants' world (Strauss & Corbin 1998). A longitudinal matrix traced each individual's before and during the programme in relation to enhanced and inhibited learning (Table 4.2).

Although these matrices assisted in identifying negative cases that inhibited learning they did not explore the influences of the participants' characteristics upon learning (Table 4.1 and 4.2) (Spencer et al 2014). It was important to understand how participants' practices varied by age and experiences. Therefore, as in this example, another matrix was created to explore extensiveness of participants' experiences of learning in light of family bereavement and experience as an HCA before the BSc programme (Table 4.3).

The columns grouped participants into those with previous experiences of giving direct EOLC as a relative or HCA, indirect EOLC through a parent's/friends distress and no previous EOLC. The rows contained the open code. This revealed the influence of previous experiences and whether these enhanced sensitivity about caring for the dying. For instance, irrespective of previous experiences in EOLC, participants did not know how to reply to patients' questions when someone died.

Each of the matrices/diagrams was accompanied by a memo that recorded initial reflections about emerging relationships. Simple diagrams were created to visually plot and view the analysis on paper. These charted similarities and differences in learning, helped immersion in the P-RNs role and revealed subtleties in conditions and context that enhanced and inhibited learning EOLC. Through the techniques described above six categories emerged, which are presented in Chapter 5 Findings. Axial memos were created to explore the relationships between categories and subcategories as in Text Box 4.4.

Table 4.2 A1 Emily: Learning enhanced and inhibited before and during the programme

	Learning EOLC before programme	First last Offices	Other experiences of last offices	Resuscitation	Learning to manage the emotional impact of EOLC	Challenging conversation	Mentors role models	Debrief	Learning in HEI	Self-regulated/ Self-directed learning
<b>Enhanced learning</b>	Grandfather died in A&E RN demonstrated sensitive communication Stimulated desire to nurse This experience helps to empathise with patients and relatives	Mentor explained the procedure during last offices	In A&E washing patient during last offices helped find closure	In A&E felt included as part of the team	Baby died in A&E Talked with RN, own family, P-RNs Write the story in a diary helped to process the grief		RN acted quickly on patients' needs RN found learning opportunities	Learning through debrief	Learn some theory in HEI Preferred small groups as it was easier to ask questions about EOLC Always remember sessions in the Skills Centre	Wanted to learn EOLC and responding to challenging conversations before qualified Aware there may not be many opportunities to learn as a RN Chose optional EOL module
<b>Inhibited learning</b>						Not allowed to observe RN and doctors talking with patients and relatives			Not enough about EOLC and last offices Not enough about managing the emotional impact No EOLC simulation in the Skills Centre	

**Key:** A&E= Accident and Emergency; EOL= End of Life; EOLC= End of Life Care; HEI= Higher Education Institute; P-RN= Pre-Registration Nurse; RN= Registration Nurses

Table 4.3 Open codes compared to difficult conversations and previous experiences in EOLC example

<b>CATEGORY LEARNING HOW TO RESPOND TO CHALLENGING CONVERSATIONS</b>	<b>Direct EOLC as a relative A1,A4,B3,C2</b>	<b>Direct EOLC as HCA/volunteer A2,A5,B5,</b>	<b>Indirect EOLC- parent's /friends distress when grandparents died B4,C1</b>	<b>No previous experience EOLC A3,B1,B2</b>	<b>Total</b>
Felt unprepared for difficult questions	A1,B3,C2	B5		B1,B2	<b>6</b>
Advice about how to respond to difficult questions varied		B5		B1,B2	<b>3</b>
Do not know how to stop conversation with patient	C2				<b>1</b>
Talk about death is taboo with some RNs			B4, C1	A3	<b>3</b>
Learn by intuition, trial and error	B3	B5		B1	<b>3</b>
Do not know what to say to patients when someone died	A4,B3,C2	B5	B4	B1,B2	<b>7</b>
Felt guilty when conversation went wrong				A3	<b>1</b>
Opportunity to practice under supervision		A5			<b>1</b>
RN stand-offish with patients and relatives	A4,B3,C2	B5	B4,C1	B1,B2	<b>8</b>
CNS role modelled compassionate communication	B3	A5	C1	B2	<b>4</b>
RN in ward modelled compassionate communication	B3,C2		C1		<b>3</b>

#### Text Box 4.4 Axial memo

##### **Axial Memo 4/2/14 Why is it difficult to communicate with patients (excerpt)**

Participants with and without previous personal or professional experiences of EOLC found communicating with patients difficult and wanted to improve their skills (**attitude-motivation**). Participants did not know how to respond to challenging questions or if a relative was crying (**learning inhibited or absent**). Participants received variable advice in the CLE so may not have developed a mental model to guide their response.

Learning was enhanced by mentors finding opportunities for them to observe nurse/doctors interactions with patients and relatives (**valued by mentor**). Participants also sought out mentors they considered excellent communicators (**behaviour self directed/regulated learning**).

There is a crosslink with emotional impact as Kate (C1) was overwhelmed by emotions and unable to talk with relatives. She was in the older age group and had cared for a parent who died which may have sensitised her to the emotional impact upon the relative (**previous experience in family**). Kate (C1) valued being supported by a kind mentor who did not make her feel alienated for crying (**enhanced learning when valued as individual**). There seems to be a crosslink with mentors creating an atmosphere where P-RNs felt safe, which encouraged learning.

Learning to communicate interlinks with the exceptional role model/mentor, emotional impact and self-regulatory learning. A consequence of feeling valued and observing compassionate communication may be learning sensitive communication (**enhanced learning**).

*Reflection on personal bias. I expected communication to be good in cystic fibrosis, cancer and hospice care but not in ITU, A&E or clinical wards due to my personal experiences as an RN and with my relatives. I tried to place these preconceptions to one side during data analysis. The transcripts revealed that there were role models who provided exceptionally good communication in A&E, ITU and medical wards. However, there were also examples of RNs avoiding communicating with patients and relatives....As the data were analysed these findings were familiar to me as a nurse. It is not easy to describe learning in discrete themes as they do not fit one theory. Knowledge was partly gained from theory in HEI but mostly accumulated from experiences and working with RNs as in novice to expert (Benner 1984), transferring knowledge from personal life experiences into work and role modelling (Bandura 1997a,b). There were elements of Maslow's (1970) Hierarchy of Motivation, and self-directed learning (Knowles 1990).*

After data analysis Strauss & Corbin (1998) recommend comparing an incident in the data to the literature. This was compared in a matrix, for instance, learning communication from a RN who might be exceptional or robotic (Table 4.4). Each row contained a finding. Columns included the researchers reflections/memo; similarities to learning theories; differences to learning theories and relevant research studies. In addition diagrams were made that showed how the findings from my investigation filled in gaps found in the meta-ethnography.



Table 4.4 Example of comparing findings to theories and literature

Finding	Researchers reflections/memo	Similarities to learning theories	Differences to learning theories	Relevant research studies
<p>Robotic hardened role model/mentor (A4, B1,B2,B3,B4,B5, C1,C2 )</p> <p>P-RNs feared they would become robotic (C1, C2)</p>	<p>This is an extensive finding across the three groups</p> <p>Robotic is a powerful term that appears inhuman or without emotion</p> <p>Participants described this as avoiding patients and relatives which were perceived as being poor care that inhibited their learning</p> <p>Worried they would become like this</p> <p>What could be the reasons for this detachment?</p> <p>Explore this further in the literature</p>	<p>Role modelling theory Bandura and Walters (1969), Bandura (1997 p30)</p> <p>Role models are more likely to be copied if admired so if not admired did not want to copy</p>	<p>P-RN may copy RN if not experienced enough to recognise the differences between good and poor communication</p> <p>Do P-RNs create their own values?</p>	<p>Describe similar comments: PRNs (Degner &amp; Gow 1988, Fulton 2008)</p> <p>Patients &amp; relatives describe 'hard nurses' (McSherry 2007), 'distant or unfriendly' (Attree 2001, Hopkinson et al 2003)</p> <p>National Survey of the Bereaved (DH 2012)</p> <p>Review of the Liverpool Care Pathway (DH 2013)</p> <p>Smith (2012) described RNs as detached/ alienated from patients</p>

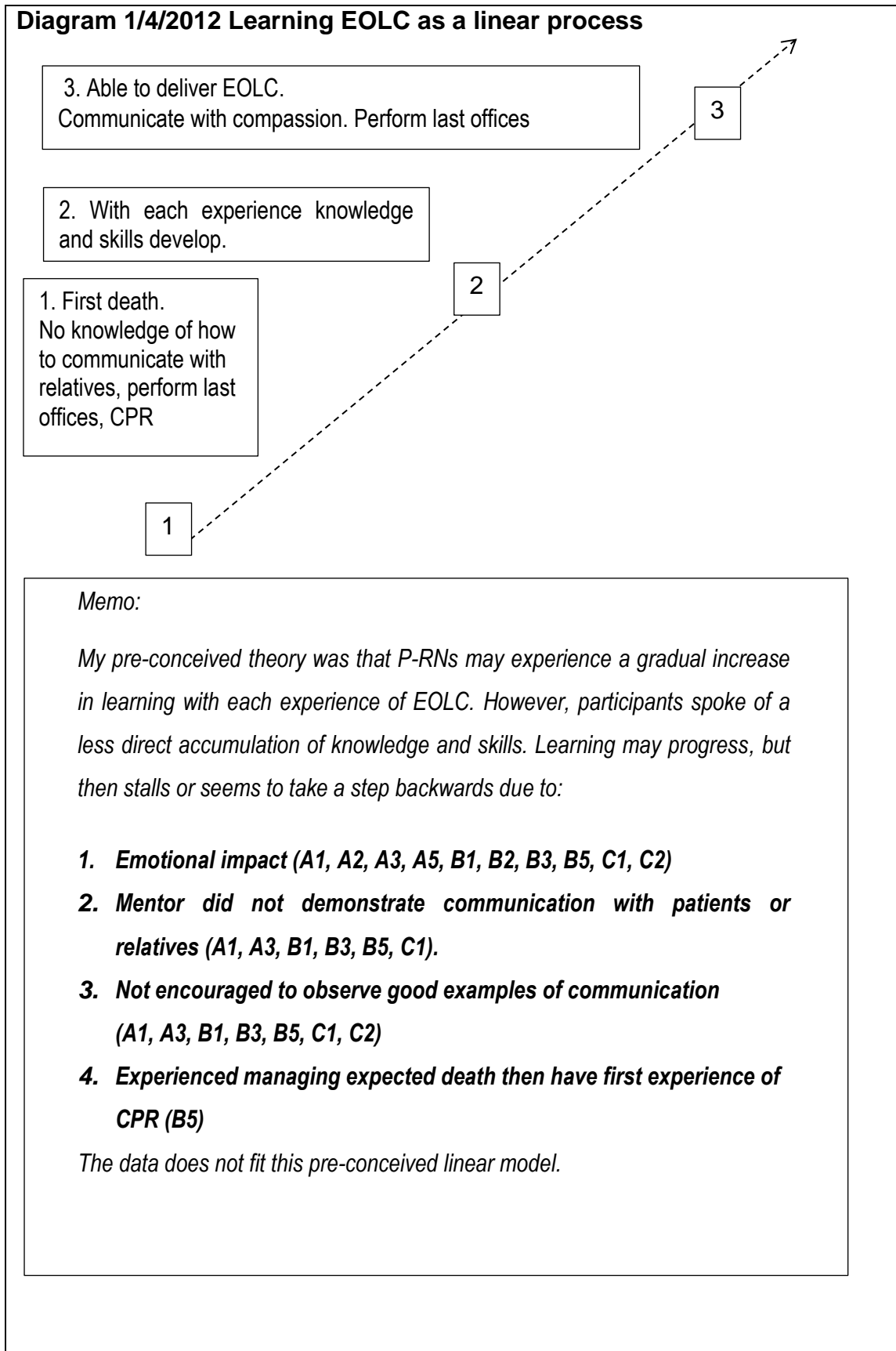
Coding for process is part of axial coding which 'examines action/interaction and notes sequences, changes and how this evolves or stays the same' (Strauss & Corbin 1998 p167). In this example of the data analysis process, I initially thought learning was a linear process, however, by reading the transcripts, drawing diagrams and writing process memos I determined that learning oscillated between two points: Novice in EOLC, and Evolving competence in EOLC (Text Box 4.5, Figure 4.1).

Text Box 4.5 Process Memo

**Process Memo 4/4/2012 Learning EOLC (excerpt)**

The process of learning does not appear to be linear. Examples were given of being upset the first time communicating with someone who was dying. The participant would then learn to manage their emotions for the next interaction. However, there were examples of then being faced with a traumatic death such as cardiac arrest (B5), death of a child (A1) or challenging questions (B2) and becoming overwhelmed. When learning is **enhanced** a participant may take a step towards competence, but an event that **inhibits** learning may cause a step towards being a novice. Thus a participant may oscillate between the two paradigms. Key features were the RN facilitating learning and participants seeking out an exceptional role model/mentor to observe (**self-directed/regulated learning**).

Figure 4.1 An early diagram mapping the trajectory of linear learning EOLC



### Selective coding

Selective coding is the process for choosing a central core category.

Techniques recommended by Strauss and Corbin (1998) were undertaken. The original recordings and transcripts were listened to, memos, matrices and diagrams were reviewed. Finally a descriptive story line was written to explore how the concepts fitted together (Text Box 4.6).

#### Text 4.6 Example of descriptive storyline

##### **Descriptive storyline 4/5/2013 (excerpt)**

It was evident that for some learning started before the BSc programme from caring for relatives or as an HCA. For others seeing their parents experience of grief and also poor quality of nursing care instigated the desire to give sensitive care. It was evident P-RNs delivered EOLC and talked with patients and relatives. There were several instances where the P-RN was with patients when they died. As P-RNs experiences developed they recognised the need to develop skills in performing last offices and sensitive communication. Those with previous experience appeared to acknowledge this earlier than those without. Participants described how learning experiences were improved by role models/mentors who explained situations, undertook debrief and found learning opportunities for them. Conversely it was evident not being offered debrief or to observe communication between nurses/doctors and patients were described and inhibited learning...Thus central to each description was the category enhanced or inhibited learning which is the core category that links all other categories. What is striking about these discussions is that these third/final year nursing students identified factors that enhanced and inhibited their learning.

From the selective coding and memos the core category emerged as 'Enhances versus inhibits learning EOLC.' This was chosen as it appeared frequently in the data and integrated all categories. The findings were then compared and translated and developed into Pre-registration nurses perceptions of how their learning EOLC could be enhanced in different contexts: a conceptual map (Figure 5.1) and Factors that enhance P-RNs learning EOLC (Figure 6.1). Five key features of learning emerged: the translation of knowledge between the HEI, CLE and P-RNs; learning through role modelling; P-RNs motivation to learn EOLC; learning to manage the emotional labour of EOLC and creating a safe learning environment. A printed copy of the matrices, diagrams and memos were kept in a Coding Folder and referred to continually during analysis and when writing the findings.

### Selecting quotations

Single quotations and sequences of conversation were selected that revealed the evidence and 'consensual piling up of fine details' (Wilkinson 1998 p115). These gave participants a voice and conveyed a sense of what it is like learning to provide EOLC in the HEI and CLE. Although participants' words were more powerful than a description, 'over lengthy quotations are tedious to read and distract from the clarity of the commentary' (White et al 2014 p383). In light of the latter comment, quotations were used judiciously, to 'ground' the complex ideas and demonstrate linkage between categories.

A criticism of focus group research has been the reporting of individuals' words and underreporting sequences of group interaction that contributed to the findings (Kitzinger 1994, Wilkinson 1998, Duggleby 2005). Group interactions can be complex and require lengthy quotations. To avoid this, quotations illustrating an open code were grouped and read while listening to the recording, to place these into the context of group interaction (Morgan 2012). The group interaction is presented as a summary of the questions and discussion that led to the findings (Wilkinson 1998, Morgan 2012). In addition, dominant members, heated discussion, arguments and consensus were reported (Carey & Smith 1994, Stevens 1996).

Group interactions are reported through a sequence of conversation to reveal the co-construction of meaning in learning EOLC. Morgan's (2012) suggestions were followed by 'actively moving back and forth between the interactive dynamics of focus groups and the content of the interaction'(p164). An element of co-construction is sharing and comparing. This was demonstrated when participants built upon a previous remark using the word 'and' or enthusiastically elaborated upon the account. While an alternative to the remark was signalled with the conjunction 'but' (Morgan 2012). Thus the analysis was placed into the context of the group process. Some contributions were part of an exploration of personal experiences. Therefore, both individual quotations and a sequence of group interactions were presented in the findings. An interaction was selected over a single quotation if the segment had more impact. For instance, responding to challenging questions in FGB produced rapid fire responses known as 'lightening strikes' because the participants were electrified by the topic (Wilkinson 1998).

Krueger & Casey (2009) recommended seeking out quotations that show specificity, emotion, extensiveness and frequency. More weight was given to quotations that showed 'specificity' by providing detail and insight. For instance David's (FGB) description of learning being enhanced by observing a CNS's conversation with a patient was more concise and specific than Joan's (FGC) example. Emotional comments were included that were forceful, enthusiastic or passionate (Krueger & Casey 2009). Frequency refers to the number of times a point was made, thus one participant may make a point several times as he/she is constructing how learning was enhanced or inhibited. Related to this is extensiveness which refers to how many people mention a topic (Krueger & Casey 2009, 2015). Quotations that shared a particular point from several individuals within and across groups were presented together to show extensiveness. This enhanced credibility as the topic extended beyond one group discussion (Morgan 2012). A comment mentioned once was also valued when it was an insightful point which no one else had considered (Krueger & Casey 2009). A quotation was selected over another when it encapsulated the point concisely. When two quotations of similar quality were found, the choice was based upon the number of times a participant had already been quoted, to ensure that each participant was represented in the findings.

### **Criteria for judging the study**

Some authors argue qualitative research should be judged on validity and reliability as in quantitative research (Maxwell 1992, Cohen et al 2011).

However, validity cannot be applied in the same way to qualitative research, as the subjective nature of the participants and the researchers' opinions, attitudes and perspectives contribute towards bias (Guba & Lincoln 1989, Sandelowski 1993). Krueger & Casey (2015) recommend Guba and Lincoln's (1989) criteria of trustworthiness are applied to promote rigour in focus group investigations. Trustworthiness demonstrates how the interpretation of the data and conclusions reflect participants' experiences through the criteria of credibility, transferability, dependability and confirmability (Krueger & Casey 2009).

Transferability is the degree to which the findings can be transferred to another context (Guba & Lincoln 1989). This investigation involved 12 participants and therefore the findings cannot be generalised as in quantitative research. Instead rigour was promoted by the thick description of participant

characteristics and the rich findings that emerged so those who read the findings and procedures can judge the degree to which these apply to their situations (Sandelowski & Barroso 2003, Krueger & Casey 2009).

Confirmability measures the extent to which data and interpretations reflect the phenomena, while dependability refers to the reliability of the data (Guba & Lincoln 1989). Both these were promoted by an audit trail recording the decisions about the study design, data collection and data analysis in memos, matrices and diagrams that verified each point made.

Credibility is achieved when findings reflect the experiences and perceptions of the participants (Guba & Lincoln 1989). This investigation was concerned with the quality of information by accurately presenting participants views on factors that enhanced and inhibited learning EOLC. This was addressed by participants being carefully listened to during each focus group and clarification being sought on areas of ambiguity. At the conclusion of each focus group, participants were asked to verify a verbal summary of the discussion. Data analysis followed Strauss & Corbin's (1998) systematic steps to constantly compare findings, identify patterns and incorporate negative cases that inhibited learning. In addition, peer debriefing with the assistant moderator and research supervisors after each focus group assisted in making decisions about findings to explore in the next group and development of moderation techniques such as probing a response.

Guba and Lincoln (1989) promote credibility through member checking to verify accuracy and validity. However, member checking has been criticised as participants may not be aware of the possible multiple realities and interpretations of the data (Sandelowski 1993, Lewis et al 2014). Member checking was planned but not performed as data analysis finished three years after collection and the participants were no longer contactable. The researcher's supervisors were expert reviewers who objectively reviewed the sampling, data collection and data analysis to reduce bias, provide a different perspective and affirm analysis (Krueger & Casey 2009, 2015).

Reflexivity was performed to establish rigour and credibility as the researcher is the instrument of data collection and analysis so may bias the findings with

personal assumptions from their experiences (Finlay & Gough 2003, Krueger & Casey 2009).

Reflexivity is defined as:

‘thoughtful, self-aware analysis of the intersubjective dynamics between researcher and the researched’ (Finlay & Gough 2003 p ix).

Finlay (2002) explains that reflection is thinking after an event, whereas reflexivity is a ‘more immediate dynamic and continuing self-awareness’ (2003 p ix). She uses critical-reflection as a term encompassing both reflection and reflexivity to explore the researchers influence upon the investigation. With the above in mind examples of reflexivity and reflection in my investigation are provided (Appendix 10, 12). In keeping with reflexivity the first person is used.

Reflexivity was performed by noting reflections in a diary and discussions with research supervisors that scrutinised how my personal experiences in EOLC and bereavement and the dual roles of lecturer and researcher might influence the research question, design, relationship with participants and data analysis (Finlay & Gough 2003). Reflexivity commenced before the investigation by reflecting upon my conversations with P-RNs delivering EOLC with limited education which stimulated this investigation. Doyle (2013) warns that exploring emotions during reflexivity without considering how these influence bias or theoretical sensitivity may eclipse participants’ experiences. Therefore, by acknowledging my feelings about friends and family who had died I hoped to place them to one side to reduce the bias upon the data collection and analysis (Appendix 12). This also sensitised me to developing questions, as my powerful learning from personal bereavement was in contrast to some P-RNs whose personal experiences resulted in avoiding people who were dying (Kiger 1994, Allchin 2006, Terry & Carroll 2008, Parry 2011). This led to asking participants ‘What experiences of caring for dying people did you have before you started the programme?’

Reflexivity about my dual role as a researcher/lecturer and the power-relationship with participants who were students in the same organisation was performed and strategies identified to reduce this conflict (Appendix 10). Subsequently I made sure I did not teach this cohort. I also considered the research design and selected focus group methodology. Krueger & Casey (2009) recommend the right moderator should be someone who knows the

topic and is open to opinions but not defensive. I reflected upon my role to maintain being a moderator rather than lecturer during the focus groups.

A few days after the final focus group, a close friend and a family member died, and so data analysis was deferred to reduce researcher distress and bias. When analysis recommenced I reflected on how I learned to provide EOLC. I did not have any formal education in EOLC and last studied learning theories 23 years before. This was considered an advantage as it limited the potential for me to force data into pre-existing theories. As the findings emerged I remained open to multiple realities and compared them to my assumptions, explored the findings with my research supervisors and then explored the theories of learning and research (Krueger & Casey 2009).

### **Summary**

This chapter has explained the rationale for using a focus group design to empower participants as experts to share their experiences and perceptions. The research methods of data collection and analysis were presented with examples. This showed how the codes were analysed to identify the categories. In addition rigour and trustworthiness were addressed. The ethical issues were identified related to strategies to reduce the dual role of the researcher/lecturer and to empower and promote the participants contributions. The following chapter presents the findings from this investigation



## **CHAPTER 5 Findings**

### **Introduction**

This chapter presents the findings, drawn from the Background Questionnaire, focus group interviews and review of the curriculum documents relating to participants learning EOLC. Participants' characteristics will first be explored through the presentation of demographic data from the Background Questionnaire. Following this other findings are presented in the categories 'Learning to manage expected versus sudden death,' 'Learning to communicate with the dying and their relatives,' and 'Learning to perform last offices.'

### **Participants' characteristics**

It was intended that participants would be allocated into focus groups based upon their amount of experience in EOLC prior to their commencement of the BSc programme and to include a group of male participants. However this was hindered by the staggered response rate and limited timeframe to recruit and complete the data collection before the P-RNs returned to their next clinical placement. Therefore, participants were allocated to focus groups as they responded to the study invitation. Focus Group A (FGA) and Focus Group B (FGB) each comprised five participants. Focus Group C (FGC) was a paired interview as one invited participant did not attend. Of the 110 P-RNs invited to participate, 14 responded. One of these opted out because they had no experience of EOLC and another did not attend the focus group. This left 12 participants to be allocated to focus groups.

#### Focus group characteristics

Demographic data from the Background Questionnaire were analysed in relation to participants' age and their experience of EOLC before they commenced the BSc programme FGA included the only male participant. Six participants were aged between 20 and 21 years old and commenced the programme immediately following school. The remaining six participants were over 22 years old, with two over 30 years (Table 5.1).

#### Experience of end-of-life-care gained before the BSc programme

Three clusters of previous experience were identified. Cluster 1 included those who cared for the dying as a HCA/volunteer or relative (Table 5.2). Within this cluster, four older participants experienced the death of a parent or had

experience as an HCA and three younger participants had experienced the death of a grandparent or as an HCA. Cluster 2 included younger and older participants who had indirect vicarious experience of EOLC through the grief of friends or parents. Cluster 3 included participants with no prior experience.

Table 5.1 Participants age, gender, codes and pseudonyms

Focus group	Gender		Age in years				Total in Focus Group
	Female	Male	20-21	22-25	26-30	31-46	
FGA	A1 Emily A2 Sophia A3 Olivia A4 Erin	A5 David	A1 Emily A2 Sophia A3 Olivia A4 Erin	A5 David			A1 Emily A2 Sophia A3 Olivia A4 Erin A5 David (n=5)
FGB	B1 Daisy B2 Amy B3 Isabelle B4 Anna B5 Rose		B1 Daisy	B2 Amy B5 Rose	B4 Anna	B3 Isabelle	B1 Daisy B2 Amy B3 Isabelle B4 Anna B5 Rose (n=5)
FGC	C1 Joan C2 Katy		C1 Joan			C2 Katy	C1 Joan C2 Katy (n=2)
<b>Total</b>	<b>11</b>	<b>1</b>	<b>6</b>	<b>3</b>	<b>1</b>	<b>2</b>	<b>12</b>

Table 5.2 Experience of end-of-life-care before programme

	Cluster 1 Direct EOLC			Cluster 2 Indirect EOLC	Cluster 3 No experience
	Grandparent	Parent	HCA or volunteer	Friends or parent's emotional distress.	
20-21 Younger	A1 Emily A4 Erin		A2 Sophia	A3 Olivia	B1 Daisy
22-25 Older			A5 David B5 Rose		B2 Amy C1 Joan
26-30 Older				B4 Anna	
31-46 Older		B3 Isabelle C2 Katy			
<b>Number of participants</b>	<b>2</b>	<b>2</b>	<b>3</b>	<b>2</b>	<b>3</b>

#### Placements where participants provided end-of-life-care

Participants had clinical placements in one of four NHS Trusts. They were asked to identify clinical areas where they had cared for the dying to set the discussion within context (Table 5.3). All four Trusts included medical and surgical wards, Intensive Therapy Units (ITU) and Accident and Emergency

Table 5.3 NHS Trusts

Focus group	NHS Trust				Total
	NHS Trust 1	NHS Trust 2	NHS Trust 3	NHS Trust 4	
FGA	A1 Emily A2 Sophia	A3 Olivia A4 Erin	A5 David		5
FGB	B1 Daisy B2 Amy B3 Isabelle	B4 Anna B5 Rose			5
FGC				C1 Joan C2 Katy	2
<b>Total</b>	<b>5</b>	<b>4</b>	<b>1</b>	<b>2</b>	<b>12</b>

(A&E), providing similar learning opportunities for EOLC. FGA and FGB included participants from more than one Trust and FGC included two friends from the same Trust.

Participants cared for the dying throughout the three year programme (Table 5.4). Eleven participants had experiences caring for the dying in medical/surgical placements in their first year including those with Human Immunodeficiency Virus (HIV) and medical conditions and/or had observed patients receiving ‘bad news’ related to diagnosis/prognosis. Participants had also cared for the dying in their second and third years of the programme, across a variety of settings including primary care, ITU, A&E, cancer units and a hospice.

#### End-of-life-care in the curriculum

The review of the curriculum documents revealed that EOLC is distributed over three compulsory modules (Table 5.5). Theoretical components of EOLC, LCP, Advanced Planning and breaking bad news were explored in the Complex Needs module. Sudden death is addressed by an annual electronic learning package and two hour skills session on cardiopulmonary resuscitation (CPR). In the third year two optional modules relate to EOLC. It is expected that last offices and recognising the signs of death is covered by the mentor in the CLE. Therefore these elements are not explored in the HEI.

Table 5.4 Where participants provided EOLC during the BSc programme.

Focus Group	Medical Ward	Surgical Ward	OPD	Medical Ward	Surgical Ward	Primary Care	ITU	A&E	Cancer Unit	Hospice	OPD
	Year One	Year One	Year One	Year Two & Three	Year Two & Three	Year Two & Three	Year Two & Three	Year Two & Three	Year Two & Three	Year Two & Three	Year Two
FGA	A1 Emily A2 Sophia A3 Olivia A4 Erin	A1 Emily A3 Olivia A4 Erin		A2 Sophia A3 Olivia A4 Erin	A2 Sophia A3 Olivia A4 Erin A5 David	A1 Emily A2 Sophia A3 Olivia A4 Erin A5 David	A4 Erin A5 David	A1 Emily A2 Sophia	A1 Emily A4 Erin A5 David		A1 Emily
FGB	B1 Daisy B2 Amy B5 Rose	B1 Daisy B2 Amy B3 Isabelle B4 Anna	B3 Isabelle	B2 Amy B4 Anna	B1 Daisy B2 Amy B3 Isabelle B4 Anna	B1 Daisy B3 Isabelle B4 Anna		B1 Daisy B3 Isabelle	B5 Rose	B5 Rose	
FGC	C1 Joan C2 Katy	C2 Katy		C1 Joan C2 Katy	C1 Joan		C2 Katy	C1 Joan			
Total	9	8	1	7	9	8	3	5	4	1	1
<p>Key:  A&amp;E= Accident and Emergency; FGA=Focus Group A; FGB = Focus Group B; FBC= Focus Group C; ITU= Intensive Care Unit; OPD=Out Patient Department</p>											

Table 5.5 Learning end-of-life-care in the curriculum

Year /module	End-of-life-care	Hours	Written assessment
Compulsory Modules			
Year One Nursing Arts and Skills	Grief and loss Groups of 20 students	2	No
Year Two Urgent Managed Care	End-of-life-care in acute settings Lecture 110 students	2	No
Year Two Complex Needs	End-of-life-care Lecture 110 students	2	One essay option.
	End-of-life-care Six groups of 20 students Problem Based Learning seminars discussing case studies and clinical experiences	2	No
	Breaking bad news Lecture 110 students	2	No
	Breaking bad news Workshop practicing SPIKES protocol (Buchan 2005)	2	No
Total Hours		12	
Cardiopulmonary resuscitation (CPR)	Annual practice with mannequin	6	No
	Annual e-learning update	6	
Total Hours		12	
Year Three Optional Modules: End-of-Life in Contemporary Society A3 Olivia B4 Anna  Facing Transition and Loss A4 Erin B5 Rose	Sessions about end-of-life-care	24	Essay
		24	Essay

In summary, each focus group included younger and older participants and those who had, and had not provided EOLC before commencing the BSc programme. FGA and FGB included P-RNs who had clinical placements in different trusts, in comparison FGC included two friends from the same trust. The only male participant was in FGA. Findings from the focus groups and paired interviews will now be presented in terms of 'Learning to manage expected and unexpected death,' Learning to communicate with the dying and their relatives' and 'Learning to perform last offices,' in relation to the participants ages and experiences of EOLC.

### Overview of the findings

In accordance with Strauss & Corbin's (1998) criteria, a core category was identified to explain other categories and the variation within these. This core

category was 'Enhances versus inhibits learning EOLC.' Factors enhancing or inhibiting learning were identified in the data in relation to the categories 'Learning to manage expected and unexpected death,' 'Learning to communicate with the dying and their relatives' and 'Learning to perform last offices,' which have been used to structure the presentation of findings below.

The category 'Learning to manage expected and unexpected death,' originated from participants reports of their experiences in both these situations. It was apparent in the data that when a person is expected to die and there is an open awareness about the patient's prognosis, this provides time to learn how to meet the needs of the patient and relatives. Also P-RNs developed strategies to manage the emotional impact of death. In contrast, unexpected death may require CPR and so provides multiple opportunities for learning in terms of roles and management of the emotional impact of unexpected death (Table 5.6).

'Learning to communicate with the dying and their relatives' was a dominant category in the transcripts. P-RNs were aware of the need to develop sensitive interpersonal skills and learn responses to challenging questions from patients and relatives. Also they learned how to manage their emotions to be able to converse without being either overwhelmed or appear to be unfeeling.

'Learning to perform last offices' is a skill participants believed they needed to develop before they qualified. There were two components to this: learning the psycho-motor skill and learning to manage the emotional impact of seeing someone who has died.

Crosslinking these three categories are three properties: context of learning; registered nurse role models/mentors' strategies; and Pre-Registration Nurses' characteristics and strategies. It became apparent that learning was enhanced or inhibited depending upon the dimensions within these properties. Whereas theory is learned in HEI, experiential learning occurs in the CLE. In participants reports, Registered Nurses were role models/mentors (RM/Ms) described as either exceptional or robotic. Exceptional role models/mentors (RM/Ms) viewed EOLC and the LCP as an opportunity to deliver compassionate care with sensitive communication. They appeared kind, sensitive and caring to patients and relatives. Moreover, they showed that they valued P-RNs by encouraging learning and self-efficacy. Participants also described 'robotic' RM/Ms who

Table 5.6 Core category, categories and properties with data source

Core Category	Categories	Properties that enhance/inhibit learning		
		<u>Context of learning</u>	<u>Registered nurse role model/mentors (RM/Ms) strategies</u>	<u>Pre-registration nurses' characteristics and strategies</u>
<b>Enhances versus Inhibits learning EOLC</b>	<b>Learning to manage expected and unexpected death</b>	<p><i>Property: Learning the theory of EOLC in the HEI (C, FG)</i></p> <p><i>Property: Learning EOLC in the CLE (FG)</i></p>	<p><i>Property: Registered nurse RMM guided reflection to learn to manage expected and unexpected death and the potential emotional impact versus no guided reflection (FG)</i></p> <p><i>Property: Registered nurse RMM explained procedure during resuscitation versus no explanation (FG)</i></p>	<p><i>Property: Potential emotional impact of expected and unexpected death due to age and previous experience (BQ, FG)</i></p> <p><i>Property: Strategies to manage the emotional impact of expected and unexpected death versus no strategies (FG)</i></p>
	<b>Learning to communicate with the dying and their relatives</b>	<p><i>Property: Learning the theory of communication in the HEI (C)</i></p> <p><i>Property: Prepared for conversations versus unprepared in the CLE (C, FG)</i></p>	<p><i>Property: Registered nurses' RMMs' strategies that enhance learning compassionate communication (FG)</i></p> <p>versus</p> <p><i>Property: Registered nurses' RMMs' strategies that inhibit learning compassionate communication (FG)</i></p>	<p><i>Property: Younger versus older and previous experience versus no previous experience of EOLC (BQ, FG)</i></p> <p><i>Property: Self-directed learning to communicate with the dying and their relatives (FG)</i></p>
	<b>Learning to perform last offices</b>	<p>HEI(C):</p> <p><i>Property: Theory of performing last offices in the HEI (C, FG)</i></p> <p><i>Property: Performing last offices in the CLE (C, FG)</i></p>	<p><i>Property: No opportunity to practice last offices (FG)</i></p> <p><i>RMM did not explain procedure or provide guided reflection (FG)</i></p> <p>versus</p> <p><i>RMM explains procedure and provides guided reflection (FG)</i></p>	<p><i>Property: Younger versus older participants and previous experiences performing versus no experiences of last offices (BQ, FG)</i></p> <p><i>Property: Self-directed learning to perform last offices (FG)</i></p>
<p>Key:                      BQ=Background questionnaire; C=Curriculum Documents; CLE = Clinical Learning Environment; CPR= Cardio-Pulmonary Resuscitation; EOLC= End-of- Life-Care; FG=Focus Group; HEI= Higher Educational Institution; PBL= Problem Based Learning; RM/M=Role model/mentor</p>				

appeared hardened to death. They delivered physical care but avoided talking with patients and relatives and were dismissive of people dying and did not always appear to value P-RNs as learners or be aware of the emotional impact on them.

P-RNs were active contributors to their learning. This was influenced by their age, previous experience, and whether or not they had developed strategies to manage the emotional impact of caring for the dying. A variety of self-directed learning behaviours were used including: setting personal learning objectives; reading about diseases and procedures; and seeking out an exceptional RM/M. Strategies to manage emotions were developed and included understanding the disease process, providing sensitive care, listening to relatives, observing mentors' strategies, personal reflection and demarcating the boundary between work and home. Managing the emotional impact of EOLC was similar between the three categories and therefore it was explored in relation to the category: 'Learning to manage expected and unexpected death.' These properties integrate with the core category, as learning was enhanced or inhibited. Each category will now be discussed in detail.

### **Category: Learning to manage expected and unexpected death**

Participants described learning EOLC in relation to two scenarios:

- 1) people expected to die within the next few weeks, days or hours and did not require cardio-pulmonary resuscitation (CPR);
- 2) those who die unexpectedly.

These two scenarios required different knowledge and skills.

Subcategory: Learning to manage expected and unexpected death:

Context of learning

*Property: Learning the theory of EOLC in the HEI*

In response to the question 'What helps you learn to care for the dying?' participants compared and contrasted their learning experiences. During year one P-RNs had attended a seminar group to discuss personal loss (Table 5.5). Older participants suggested this enhanced their learning by exploring their emotions. Daisy (FGB: L456), Amy (FGB: L471) and Joan (FGC: L817) who had no previous experience in EOLC did not remember the compulsory



session. It is unclear why they did not remember, but participants suggested that P-RNs are overwhelmed with new information during the first year so that 'lectures merge together' (FGA: Emily L474). Alternatively the participants may not have attended, or EOLC becomes meaningful after experiencing care-of-the-dying.

During year two the theory of EOLC and unexpected death is delivered during lectures and PBL groups (Table 5.5). Some participants reported that their learning was enhanced because experienced lecturers explored the key points about EOLC (FGA: Sophia L379; FGB: Amy L437; Anna L439; Rose 440-448; FGC: Joan L812; Katy L863). However, some felt their learning was inhibited by feeling too intimidated to ask questions in the context of a lecture delivered to 100 students. In contrast participants described how learning was enhanced in the smaller groups comprising twenty students in which they explored a PBL case study and could discuss a patient's deteriorating condition (FGA: Emily L355-360, L385; Sophia L361; Olivia L431; David L570; FGB: Amy L440-443; Anna L452; FGC: Joan L435; L813; Katy L861).

Although sessions in HEI appear to contribute to learning, some participants with previous experience believed that more EOLC content was required in the curriculum so that students felt better prepared:

Erin: 'There was not enough on care-of-the-dying patient. What you do when a patient dies or starts the LCP... Mostly you learn in practice, but I think it helps to have a lecture to backup what you are doing so you know it is right... this may be in the pre-placement talk.' (FGA: L372-392).

A widespread perspective was that the theory is taught in the HEI but main place to learn EOLC is in the real world of interconnected influences in the CLE as evidenced by this comment:

David: 'Yes there was an emphasis upon training to be an academic and get the theory right, but when it comes to the practical nitty-gritty stuff, it is harder to do in a lecture' (FGA: L447-449).

In the HEI, PBL scenarios may be based upon a patient with a single disease and supportive family members. However, in the CLE, patients often have multiple morbidities and symptoms. They may have complex social histories with multiple partners and children who may be angry, accepting or crying, so

the idiom 'nitty-gritty' suggests important aspects of EOLC are learned in the CLE.

*Property: Learning EOLC in the CLE*

In response to the question 'What helps you learn to care-for-the-dying?' participants also described that most learning was alongside a RN who was a role model and mentor (RM/M) and hinted that the CLE also influenced their learning. Participants described learning being enhanced in areas more prepared for EOLC, such as ITU (FGA: Erin L168; David L184; FGC: Katy L243), A&E (FGA: Emily L142; Sophia L202; FGB: Daisy L124; FGC: Joan L277), hospice (FGA: Sophia L44; FGB: Rose L121-123; FGC: Katy L243), cystic fibrosis unit (FGC: Joan L533-543), care of the elderly and medical wards (FGC: Katy L250; Joan L247-249). Alternatively, in areas that rarely experienced death, nurses often lacked the knowledge or skills to deliver EOLC which inhibited P-RNs learning (FGB: Daisy L399; FGC: Joan L254-256; Katy L267-262). These diverse perspectives were encapsulated by Joan and Katy who worked in the same trust. Whereas Joan was a younger nurse without prior experience Katy was older and compared her experiences with a parent in a hospice to EOLC in a hospital setting. This longer conversation has been edited:

Katy: 'We went into a room [at the hospice] and the RN put on music and a water feature, it was just so nice, but that is the hospice experience.'

There is all this talk about hospice at home or hospice in the hospital and you think of those sorts of niceties. But it is just impossible, even with the LCP and the planning to make it into such a nice experience. It would be lovely, but it is just impossible as the whole structure of the ward and the logistics of the ward it just does not work.'

Joan: 'I think it depends upon the ward, like you said ITU, medical and elderly care wards are very good at dealing with death as they do it every day. Whereas you get surgical wards...'

Katy: '... People are not meant to die there.'

Joan: '.... Nurses did not like people dying, it is not common, and the general view was that it is not natural to die on a surgical ward and they were not equipped to deal with it.'

Katy: 'If someone was receiving the LCP it is 'oh well we do not have to do anything for that person.' They gave physical care but it was a bad attitude. Whereas, on the medical wards with a good mentor, they were short staffed but the attitude and the whole ethos is that this is a good

place to be and a positive start to this person's final journey. Whereas, nurses on the surgical ward, 'Oh well that is it then!'

Joan: 'No obs.'

Katy 'Yes don't do obs.'

Joan: 'Don't bother about it' (FGC: L243-264).

This conversation reveals the differences between the calm hospice environments that only focus on EOLC, compared to the busy hospital which balances the demands of acutely ill patients with those who are dying. This is important as an environment that promotes compassionate EOLC may encourage the mentor to support P-RNs learning. It was suggested later in this conversation that compassionate EOLC was influenced by the nurse patient ratio, inter-professional decision-making and the ward manager.

The ratio of nurses to patients is higher in ITU than in the wards. In ITU P-RNs observed a RN, who could explain the procedures as they worked together so that the 'one to one nursing can provide such fabulous care for somebody focused upon learning' (FGC: Katy L643-645). Whereas, learning EOLC in hospital wards, occurs alongside acutely ill adults as illustrated by Daisy a younger participant without prior experience, during her first placement in a medical ward:

Daisy: 'I think that it is very difficult as you sometimes have people who are ill needing regular medication. It is just so difficult. I remember my very first experience in my first placement. This lady was 'put' in the single room, she was very anxious. The nurse I was working with did not know what to do. It was such a busy day and the nurse had 10 patients. I was only a first year student, so I was doing my bit to help but it was just such a difficult situation, really difficult. That lady died over night. I felt sad and upset as I did not know if I made that lady's last day as she would want. She was so anxious and there was not anything anyone could do. I think it is just so difficult on busy wards to give the care you really want to give' (FGB: L396-496).

Daisy's example reveals how P-RNs may be caring for the dying during the first clinical placement. She appears frustrated with her lack of skill to respond to this lady. Daisy's experience contrasts with Katy's 'fabulous care' in ITU and the calm hospice environment. The repeated use of the word 'difficult' reveals the challenges and problems faced by P-RNs and RNs who balance the demands of EOLC with those of the acutely ill and feel unable to provide the care they

wish to. This also illustrates the tension in the role of RN who has a burden of patient care as well as promoting P-RNs learning.

Participants across the three groups described how EOLC was enhanced by learning from inter-professional decision-making. This was more evident in settings where death was more prevalent such as in A&E (FGA: Emily L144; Sophia L213; FGB: Daisy L165-172; FGC: Joan L443-447) ITU (FGA: Erin L219-234; FGC: Katy L448-452), hospice (FGB: Rose L190-195) and a cystic fibrosis unit (FGC: Joan L528-532). In these cultures medical professionals, doctors, RN's, dietician's, physiotherapist and occupational therapist's shared their knowledge and expertise to enhance learning between the professionals. As three participants explain:

Joan: 'From my experience doctors listen to nurses in ITU and A&E, whereas, in a general ward the manager is listened to by doctors, but any other nurses knowledge is taken for granted.'

Katy: 'I am in complete agreement with you because the MDT works in ITU when everyone is around the patient's bed talking and making decisions every 10 minutes if that is required. Whereas on the ward doctors will be on the rounds or just making decisions not at the patient's bedside but at the nurses' stations or the corridor and the nurse is not there' (FGC: L443-452).

Emily 'In A&E ...that is really nice as you are acknowledged as part of the team and you have a say. It is comforting to know you are working as a team' (FGA: L213-217).

Katy suggests inter-professional learning is hindered by the infrequent doctors' visits to the wards compared to A&E and ITU. The phrase 'taken for granted' (FGC: Joan L447), suggests RNs knowledge is not valued by the medical team in contrast to ITU, A&E, hospice and cystic fibrosis units. It may be that RNs in ITU and A&E have developed technical knowledge including advanced assessment, nurse prescribing and advanced life support which doctors' value compared to personal hygiene in the wards. Joan, described two medical wards in which learning from inter-professional decision-making appeared to be influenced by the ward manager:

Joan: 'The ward was complicated. They did not have management so it was disorganised. There was a lot of ward politics between nurses and I did not have a good time...' (FGC: L315-317)

...‘If the ward has an MDT meeting it tends to be with the non-clinical ward manager who gets information from the nurses notes not from the patient’ (FGC: L454-455).

Although learning was reported as taking place alongside the RM/M, the ward managers appear to be instrumental in creating an environment that enables or inhibits the transfer of knowledge.

In summary, learning to manage expected and unexpected death appears to be influenced by the context in which theory is learned in the HEI. Learning in the CLE is influenced by a culture that values compassionate EOLC. The sequence of theory delivery and varying EOLC in the CLE reveal the dichotomy in core category ‘Enhances versus inhibits learning EOLC.’ The strategies and characteristics of RN RM/Ms that enhanced and inhibited learning are explored in the next section.

Subcategory: Learning to manage expected and unexpected death- Registered nurse role model/mentor strategies

Participants described learning by observing exceptional RM/Ms as they provided symptom management and hygiene needs for people expected to die. Learning also occurred during an unexpected death when P-RNs observed the techniques used by health professionals during cardiopulmonary resuscitation. These participants explained how learning was enhanced further during conversations with RM/M.

*Property: Registered nurse RM/M guided reflection to learn to manage expected and unexpected death and the potential emotional impact versus no guided reflection*

In response to the question ‘Can you give me examples of what was supportive when caring for the dying?’ a widespread perspective was that mentors instigated conversations following a death or cardiac arrest. These were termed ‘reflection’ (FGA: Erin L590-593; Olivia L608-611; FGB: Rose L191-204; Isabelle L481-483; FGC: Joan L935-939; Katy L373-377), ‘debrief’ (FGA: Erin L628-629; David L187-192, FGB: Daisy L185-188) and ‘clinical supervision’ (FGB: Rose L191-204). These terms all described the provision of an opportunity to learn by exploring why a person died and how this knowledge could be applied to future patients. In these examples guided reflection/debrief/clinical supervision were initiated spontaneously by a

doctor/nurse when a patient died unexpectedly and during a weekly forum in a hospice for those expected to die. Common settings for the examples given were: ITU, A&E, cancer units and some medical wards where there was a culture of using reflection/debrief to enhance learning. The focus of the reflection varied. Whereas multi-professional debrief explored the medical decisions, one-to-one reflection with an exceptional RM/M enhanced individual learning.

Participants reported mentors who were exceptional at guiding them during reflection and used several strategies that enhanced learning. Firstly, the mentors created a welcoming safe environment. They were kind and showed empathy by acknowledging the potential emotional impact and giving P-RNs permission to be upset. In addition, participants were given permission to leave the area to compose themselves prior to a meeting with the mentor to reflect on the event. Participants valued this recognition of their feelings and seemed to respond by becoming interested and enthusiastic learners. Secondly, exceptional mentors appeared to want to share their knowledge and experiences. Rather than testing the participants' knowledge, this interaction appeared to result in a deeper understanding by exploring the theory of symptom control and physical deterioration with a rationale for nursing and medical interventions. These components are encapsulated by Erin and David's mentors in ITU:

Erin: 'I had a mentor who said go and take 15 minutes and have a cup of tea. Then we went and sat in the bereavement room because it was empty and quiet and we could shut the door. He said if you want to cry then cry. We talked about all the situations leading up to it. It was really helpful. He brought in all the patient notes and observation charts. It was really sudden and they did not expect it. Looking back at the charts it helped me to adjust my practice, for when I qualify, in noticing the deterioration and the little changes. He explained the physiological changes that led up to it. It helps to understand the human body...You always feel pressure from other qualified nurses around you, to know the answers, and you are trying to piece together why this patient just died because he seemed fine. It was good to go through that in a quiet place where you did not feel you were being judged and nurses do not look at you as if you are silly if you are upset. That was a very helpful way of doing it...an important lesson. It opens our eyes...'

David: 'My first patient who died, which happened recently. The nurses were very supportive. I had been with that patient all day, then she suddenly she went downhill and died. The charge nurse took me into his office and did the same sort of thing. That was so invaluable to look

back right there at the time to do a debrief and evaluation. We did the best we could, but if it happened again this is how we could do it differently. It was a learning experience.'

Erin: 'It opens our eyes doesn't it and makes you more aware of the way you do the observations and interpret the results. Rather than OK the measurement is within the normal range, it is recognising that there is a significant drop in the pattern.'

David: 'We tend to remember more what we are emotionally engaged in don't we. So hearing in a lecture, then having that experience and getting immediate feedback you remember that so much easier' (FGA: L167-198).

This appears to have been a meaningful learning experience for both David and Erin as it was based on real patients, rather than being a passive learner in a lecture. These conversations appear to explore the existing knowledge from the HEI and previous experiences, then generate new knowledge to be used in the future. Emily was inspired by an encounter with a RM/M to also 'include students in the decisions and explain what is going on at the end-of-life' (FGA: L250-254), when she becomes a RN to perpetuate sharing knowledge with future P-RNs. In contrast Erin also describes learning being inhibited by mentors questioning when she did not understand the physiological process of the disease.

Several participants described learning when to implement resuscitation. They learned to keep information about a patients' resuscitation status to hand. If a patient stopped breathing and was not for resuscitation they would close the curtains and get a RN as described below by Joan who had no prior experience but had learned by the final year:

'I looked at the patient. I was pretty sure that she was not for resuscitation but I double checked my hand over. I closed the curtains and said to the other student the patient had passed away I am going to get a qualified nurse' (FGC: L284-288).

In contrast, if the patient was for resuscitation they initiated CPR as described by Rose. She had six years previous experience as an HCA and had developed strategies for caring for people expected to die, but this was her first resuscitation. A patient had a respiratory arrest while she was washing him. Rose automatically responded with CPR, called for help and assisted the anaesthetist. Following the transfer of the patient to ITU her emotions became overwhelming:

Rose: 'It really traumatised me, because I was not expecting him to go like that. I knew him during the last 2 weeks of the placement...It is very different when someone dies on the LCP. I do not know how you compare them it is impossible...I got him to ITU then I was shaking I just burst into tears and was sent for a tea break. Everyone was very supportive but I felt I should have coped with it better... Both my mentors and the staff nurses, said how well I coped with the situation at the time...The registrar was next to me and gave me the rebreathing bag, and I was doing it! I went into autopilot, and everyone said I did really well. I sat down with my mentor, a couple of days later like a clinical supervision and we just chatted about the situation and exactly what happened. I was lucky I had a good relationship with my mentor and the staff were supportive. Even the crash team said the nursing team were very good. What could have been a really horrific situation was good' (FGB: L139-163).

Whereas, there is time to plan the care for a patient expected to die, this unexpected death required an immediate response. Rose appears to have learned how to apply the theory of CPR in the real clinical setting. The words 'traumatised,' 'horrific,' 'shaking' and 'crying' reveal P-RNs vulnerability during resuscitation, even with six years previous experience as a HCA. The mentor recognised Rose as an individual by valuing her contribution as a team member and acknowledged it was normal to be upset. The guided reflection/debrief appears to have been encouraging and promoted self-efficacy for Rose to initiate resuscitation in the future. This situation encapsulates aspects of the exceptional RM/M who turned this into a meaningful learning experience. There were no examples of learning to perform CPR being inhibited.

There were no examples of learning being inhibited during guided reflection/debrief. However, opportunities to learn how to apply theory in practice were often missed when reflection was not offered:

Olivia: 'The experience you had in Intensive Care [reflecting upon the death of a patient] might be more prevalent. I have never had an Intensive Care Placement. I have never had someone sit down with me and talk through what has happened to that patient. Even after traumatic deaths' (FGA: L432-435).

A possible explanation for this lack of reflection/debrief may be due to death being less prevalent, or a higher ratio of nurses to patients in ITU may permit more opportunities for reflection than a lower nurse to patient ratio. In one example a request for reflection/debrief in ITU was refused when a patient had died unexpectedly and one of the P-RNs knew the patient and her family socially. As a result of the lack of opportunity to reflect, the participant did not



appear to feel valued as a learner and the potential emotional impact was not recognised:

Katy: 'Student X had said, 'Are we going to get together about this?' and the unit manager said 'No don't be so ridiculous.' ... It had been such a supportive environment it was all about learning and all the staff were a very good team....so there was an atmosphere and shock because we had expected much more from that environment (ITU)' (FGC: L958-965).

The word 'shock' reveals the divergence from the support that usually permeated this placement. One interpretation for this change may be that the manager may not have realised the P-RNs did not understand the event or recognise the emotional impact upon them. Alternatively, the manager might have been too busy to respond, and hence an opportunity to transfer knowledge into practice was missed. These, participants appeared to have developed a set of personal values that enabled them to differentiate between unsupportive and supportive behaviour. This example reveals the dichotomy in core category 'Enhances versus inhibits learning EOLC.'

*Property: Registered nurse RM/M explained procedure during resuscitation versus no explanation*

Participants wanted to understand RNs' and doctors' roles during resuscitation before they became registered nurses. Participants recalled their first experiences of resuscitation. These were potentially frightening and confusing as P-RNs struggled to understand new terminology, abbreviations and the significance of what was happening. Learning was reported to be enhanced when a participant was guided by an exceptional RM/M explaining differing roles and interventions. This was evident in Olivia's example during her first placement. Olivia was a younger participant without previous experience of CPR. Her perception appears to change from confusion to meaningful learning:

Olivia: 'There were lots of people it was like vultures...But there was one clinical nurse specialist and she stood next to me and just went through every step of what was happening. If you are standing there by yourself it is difficult to make sense of the sequence of events that you are not used to. You do not know why they are doing it and what led up to the event. That was really helpful' (FGA: L240-247).

The metaphor 'vultures' suggests attacking a body chaotically without dignity or respect and seems to encapsulate Olivia's confusion with different roles and interventions. It may be argued that this mentor untangled the chaos into a

structure that became an important basis on which Olivia could then build a deeper understanding. Without this valuable translation it is unclear what Olivia would have learned.

P-RNs learn the skill of CPR in the HEI and there were several examples of P-RNs being encouraged by RNs and doctors to undertake cardiac compressions in A&E (FGA: Sophia L204-207; FGB: Daisy L100; Isabelle L579) and ITU (FGA: Erin L231). CPR may occur frequently in both these areas and consequently a culture of learning this skill has developed. In one example a participant during their second year was asked to perform cardiac compressions on a patient who collapsed while being discharged from A&E.

Sophia: 'It was the first time I had done cardiac compressions. The entire time I was doing it my mentor stopped what she was doing and she was standing by my side talking me through it and telling me it was going to be ok and I was doing really well' (FGA: L204-207).

The participant explained how her learning was enhanced by the mentor guiding the procedure and praising each step.

Subcategory: Learning to manage expected and unexpected death.

Pre-registration nurses' characteristics and strategies

*Property: Potential emotional impact of expected and unexpected death due to age and previous experience*

A persistent theme was learning to manage the emotional impact of death, as each one is a unique emotional experience. Learning to manage emotions did not appear to be a linear or sequential process whereby a participant's first experience of caring-for-the-dying resulted in all the subsequent experiences being less emotional. Instead learning appeared to be a dynamic process that oscillated between an emotional response and emotional management. This may be influenced by the type of death and previous experiences. For all participants, including those with and without prior experience of EOLC and irrespective of their age, there was a potential emotional impact of grief and sadness associated with their experiences of death and dying. This was especially emotional when a young person was expected to die or the bereaved were young (FGA: Emily L114; FGC: Joan L26; Katy L52). Unexpected death could also be traumatic when initiating CPR (FGB: Rose L139-163).

Conversations with relatives revealed the patient as an individual and hence created sadness:

Daisy: 'They were saying about their mother who had been a midwife and it brought it all home to me that this lady and the person she had been was no more. It was just so sad' (FGA: L180-183).

Katy: 'We had such a lovely night for about three hours I sat chatting with his daughter. He sounded like a super person, full of stories and we had a therapeutic night...' (FGC: L469-471).

Joan: 'This lady with dementia who was dying who I would wash and feed each day. The family would talk to me about their mother's life as a nurse... On the last day they came in and said thank you...we have had a great time with our mum and you. I got upset and cried' (FGC: L782-787).

The participants in this investigation are in transition to becoming RNs and appeared motivated to learn EOLC, perform CPR and manage their emotions to be able to support other nurses as well as the patient and family. Therefore learning to manage the emotional impact was imperative to provide EOLC.

*Property: Strategies to manage the emotional impact of expected and unexpected death versus no strategies*

To explore the strategies used to manage the emotional impact each group was asked 'Where do you get support, when you feel upset when patients have died?' Participants learned from observing mentors 'attitudes' (FGC: Joan L276) and 'trial and error' (FGB: Isabelle L556). These were divided into managing emotions in the clinical areas and after the shift.

For some participants learning EOLC may have started before they commenced the programme. Previous personal experiences caring for family members may have enhanced or inhibited learning to manage their emotions. Some participants drew upon their previous personal experiences to provide a meaningful positive contribution to the care of patients and relatives. One example is Olivia, a younger participant, who spoke about how her mother's distress at the poor care her grandparent received influenced her desire to learn to provide care with dignity and respect. In response Emily shared how caring for her grandparent enhanced the empathy and compassion she feels for relatives:

Olivia: I had not worked in healthcare I came straight to college. The only experience I had was my Nan who I was very close to and passed away when I was 10-11. I do not remember much but Mum was very upset she always had the feeling that the care in the hospital was not very good and they did not treat Nan right. It is really very difficult to

think that someone you love is being treated without dignity and respect, just the basic needs...I wish Nan had a better end to her life... It is much harder to get over the death when you feel like someone was not cared for in the right way... When I have someone who is dying I think back to it and want to deliver care in the way I would have wanted my Nan to have. I think that changes how I am as a student nurse...' (FGA: L100-119).

Emily: I think when it happens to you, you think it is the worse feeling in the world. I think relatives there thinking just as I did and it helps you understand' (FGA: L120-123).

These shared experiences reveal how the impact of having been a relative creates sensitivity to relatives and patients. Olivia and Emily seemed to have transferred their learning from personal experiences into compassion that underpinned their care of patients and relatives. Past experiences may potentially evoke sad memories that might impede learning as exemplified in this discussion:

Rose: 'I think if I had gone into my nurse training without that experience as an HCA it would have been more difficult...

Isabelle: I have been concerned that I might not be able to have a handle on my emotions especially, with caring for my parent who was dying... But I have managed to still give really good care...

Anna: May be it is to do with patients. If you are not that close to them, it is not as difficult but as you get attached it is harder. There is the pressure on us to be professional and not to get upset.

All: Yes absolutely (FGB: L228-244).

These participants shared and compared their personal experiences as a relative or an HCA to co-create an understanding of the emotional impact of EOLC. For Rose being an HCA before the programme had given her the opportunity to learn how to manage her emotions. Isabelle, an older participant explained how she was inspired to become a nurse after caring for her dying parent. Initially Isabelle withheld sharing her personal experiences, then encouraged by the other participants sharing their fears and concerns, she began to express her fear of flashbacks. In this investigation none of the participants appeared to avoid patients due to personal bereavements. The conversation continued by exploring learning to delay the emotional impact:

Isabelle: 'Often I find I can keep a lid on it and then I get home and oh no, I really feel for them.'

Anna: 'I have managed to keep it together when at work, then it hits you later at home.'

Daisy: 'I think I am the opposite. It has definitely hit me a couple of times...I actually had a few tears down my face. The nurse next to me was really good and said 'that is fine, the family do not mind. If you need to take a break then just step outside.' I did not have previous experience to learn from and came straight from school.'

Rose: 'I definitely feel my emotions there and then. I do not think there is anything wrong with having a few tears... showing that you do actually care. At the end of the day we are all human and we do have emotions and we see a lot more trauma and sad situations than other professions. It does not mean that we don't feel it less.'

Isabelle: 'I think that families really appreciate it that it is not just a job but that we care.'

Daisy: 'Yes, it is not just a job' (FGB: L244-266).

As an HCA Rose had learned to postpone her emotions until after the shift. The others were initially distressed and learned how to manage the impact during the programme. Being sensitive to relative's distress appears to be seen as an important component of demonstrating compassionate care. Sophia who had prior experience as a volunteer in a hospice suggested that nurses should be compassionate:

Sophia: 'I do not think you ever harden to death. It never fails to upset you. The minute you do not become upset you should not be a nurse' (FGA: L132-133).

Therefore, among these participants their previous experiences rather than age influenced learning to manage the emotional impact of EOLC.

Participants across the three groups rationalised the patient's death as a 'relief as the patient was elderly' and 'wanted it all to be over' (FGC: Katy L99-101), 'in pain' (FGA: Emily L199-205; FGC: Joan L293), 'has dementia' (FGC: Joan L789-798) 'celebrated their life and come to terms with their terminal illness' (FGB: Rose L121-130) and 'whatever you do it will happen' (FGA: Sophia L460). Also, making these patients more comfortable and listening to the family appeared to turn participants' sadness into a rewarding experience that was a privilege, as in this group discussion:

Daisy: 'Turning those emotions around to something positive by putting them towards helping the family to get through that very difficult time.'

Anna: 'And really making sure you give the best possible care you can making sure their hair is washed and clean really give 100% looking after them. And you feel you are doing a good job.'

All: 'Yes.'

Amy: 'Yes, because often you feel it is out of your control. They might have pain and you can give them pain relief. You feel you are doing something to make them more comfortable.' (FGB: L284-292).

Daisy articulates a deeper understanding of the process in which her emotions are converted into prioritising the care of patients and relatives. The interaction with Anna and Amy helps to elaborate on this knowledge by exploring the different approaches to delivering sensitive nursing care, so that, making an individual's last days comfortable seems to be cathartic and creates a feeling of self-efficacy.

When asked how they learned to manage their emotions outside the clinical area, a widespread strategy was talking to nursing friends and relatives who understand the demands of the role. P-RNs face situations beyond the everyday life experiences of most lay people and expressing their feelings and emotions to those most likely to understand following a traumatic event may be vital for their wellbeing. Participants expressed empathy by discussing their experiences and being compassionate to each other.

Some participants without prior experience felt guilty learning from people's distress. None of the participants who had been a HCA identified this, suggesting they may have already learned to accept this influence upon learning. Erin illuminates this and by sharing her concerns with peers, learned to manage this feeling:

Erin: 'At the start it felt like you were using someone's awful experience for your own personal gain.'

All: 'Yes.'

Erin: 'I think 'how am I going to help someone else if I have never experienced it?' It is getting over that barrier. Feeling what I am doing is right for me, but it feels so wrong... I want to help other people which is why we come into nursing. At the time you feel like you are the only one to feel that. I think 'God I am so selfish! It is just about me, this is not why I came into this' (FGA: L548-558).

Recognising other P-RNs' feelings appeared to help participants learn to manage their feelings. Learning to manage emotions was enhanced by the

compassion and empathy between participants' social interactions as Katy illuminates:

Katy: 'We are the sort of people who like to open up and talk and do not find a problem with this. We always joke about how much time we spend reflecting. I mean I have probably always done it because I love to chat over a coffee with my friends. I did not call it reflection, but now I call it reflection and learn and grow from this' (FGC: L362-366).

Sharing feelings and reflecting on concerns with a social network of friends who understand the demands of the role appears to help build coping strategies. These P-RNs recognised distress in each other and purposefully used their empathy and knowledge to support each other. Katy is an older participant whose parent died in a hospice which gave her an insight into the effect of grief. Consequently Katy's personal experiences may have given her the skills to be supportive to younger inexperienced colleagues. These conversations appear to be more than a descriptive chat, as an outcome is 'learning and growing,' suggesting the development of emotional maturity. Therefore, social support appears to be an important component of learning to manage the emotional impact to enable EOLC.

Conversely, participants hid their feelings from their families and avoided talking with non-nurses who had not faced issues of life and death, so may not have understood (FGB: Amy L269) as encapsulated by Katy:

Katy: 'You do have to be mindful when you go out with friends or go home and talk to your partner. Especially how when you are talking about death how it could seem callous and you are uncaring, because you may say things that seem completely natural and normal to another nurse' (FGC: L376-379).

Talking about dying, may make people feel uncomfortable, so P-RNs may be selective about what they discuss. Some participants learned to purposefully reflect upon situations and release their emotions before they got home, to separate the two environments as illustrated by Amy and Rose:

Amy: 'I usually like to walk home after work and think about the day and how I have acted and may be what could I have done differently or why things happened the way they happened. So that by the time I get home I can leave things from the ward behind... You don't just want someone who will listen but someone who can say I have had that experience too and do not worry about it...' (FGB: L269-274).

Rose: 'Just allowing yourself to have a good cry' (FGB: L277).

In this situation these participants appeared to need to express their feelings, to physically and mentally distance themselves from the events. However, demarcation may be difficult when the event is emotionally traumatic, as for Emily after witnessing the death of a baby in A&E. She talked with her mentor, went home early and talked with friends, however the emotional impact was still there and by trial and error she found a way to live with the experience:

Emily: 'Five nights later, it was still on my mind. I was upset and wrote it down, not formally, or typed but just in a diary. It felt so right and just so helpful. It was like letting go, putting it into words, closing it and putting it away. I am not one that usually writes anything, but it helped. It was really good to do' (FGA: L600-607).

The emotional pain can last for a long period of time and was still evident during the focus group discussion. Reflection with mentors and friends may not be enough to manage grief. The phrase 'letting go and closing' suggests the process of expressing feelings by writing the story and placing it mentally and physically into another container. This may help to understand the event and consequently learn how to manage the emotional impact. This may allow the participant to explore the different components about the event. It can be hypothesised, that despite reflecting with mentors and friends there needs to be an innate ability to manage personal emotions from an 'inner strength' (FGA: Olivia L153). It is unclear if managing the emotional impact can be learned by developing strategies. Joan described another student who was 'thinking of quitting' because she was unable to manage the emotional impact (FGC: L917-920).

Participants co-constructed the gaps in their knowledge and suggested strategies to enhance their learning. For these P-RNs learning EOLC appeared to be inhibited by the lack of advice in the HEI and CLE about managing the emotional impact. Therefore participants requested a session before the first placement to explore what to expect when someone dies; to acknowledge that it is alright to be upset and where strategies other P-RNs found helpful could be shared to be used in the CLE, among friends and in the HEI as in this discussion:

Erin: 'more about coping mechanisms...'

Sophia: 'A lot of the time the wards are so busy you don't want to go to your mentor. But if you have been given a few pointers from the



college, you could ask to get involved... That it is ok to request a 15 minute break when upset. It is about reassurance.'

All: 'Yes.'

Erin: 'Reassurance it is ok to deal with death in your own way. These strategies have helped some students and may help... May be in the pre-placement talk' (FGA: L385-396).

### **Category: Learning to communicate with the dying and their relatives**

Some participants described their conversations with patients and relatives as 'providing help by listening' (FGC: Joan L48) and a 'privilege' (FGC: Katy L496) as they had time to talk with them. However, some conversations were challenging as patients initiated discussions about their prognosis and diagnosis following consultations with the medical team. Nevertheless, it was considered important to learn how to reply as evidenced by Isabelle and Amy:

Isabelle: 'It is just so important we get it right. I sometimes feel I am under a lot more pressure when caring for someone who is dying because it is just so important.'

Amy: 'I want to be able to say things that are comforting, that are not being patronising or insensitive. I have had family members call up and say, 'Shall I come in and if I come in tomorrow will that be too late?' How to try and be sensitive and also giving news that is not good news, trying for it to be a beneficial conversation with the family or with the patient' (FGB: L377-385).

There seemed to be an implicit fear about what is and is not acceptable as well as a lack of confidence. This was evident in participants' comments regardless of whether they had previous personal or professional experience in EOLC. Therefore, it is pertinent to explore properties that enhance and inhibit learning to communicate with patients and relatives.

#### Subcategory: Learning to communicate with the dying and their relatives.

##### Context of learning

*Property: Learning the theory of communication in the HEI*

In response to the question 'Do you have any sessions on communication about breaking bad news?' participants revealed that learning to respond to challenging conversations was explored in HEI during an all day workshop in year two (Table 5.5). The morning comprised a two hour lecture about the theory of breaking bad news by a lecturer experienced in EOLC. This was

followed by workshops in which 20 students explored how to respond to difficult questions such as delayed discharges guided by the SPIKES communication protocol (Buckman 2005, De Souza & Pettifer 2012). Practising the SPIKES protocol may enhance participants learning by supplying a structure to prepare for a conversation and an opportunity to practice away from the CLE. This also provided feedback and an opportunity to reflect upon their experiences in the CLE. However, participants did not describe if the SPIKES communication protocol inhibited or enhanced their learning to communicate with patients and relatives. A request from several participants was to build interpersonal skills into the existing acute deteriorating patient simulation sessions as evidenced by this conversation:

Erin: 'It could be over at the skills centre as it is such a wonderful place and the fact you have got everything there to set up this environment for first, second and third years. Say 'this patient (a dummy) has died and I want you to go through the process. We have got some of your colleagues, who are going to be the family and just run through what you would do as a registered nurse.'

Sophia: 'Yes we have a simulation of patients who are living and saving them through the actions we take as a team. But we have never heard of a simulation when your patient passes away.'

David: 'Exactly.'

Sophia: 'They said to us "Do not worry you cannot kill this patient" We all know that sometimes you can do whatever you can and it is going to happen anyway' (FGA: L450-463).

The simulation focused upon a patient's recovery, but this may have inhibited learning as the participants have a realistic outlook about life and death. This suggests that participants perceived learning sensitive communication with relatives is an important aspect of EOLC. A further suggestion was to learn breaking bad news with medical students as this may allow an insight into each other's roles and develop rapport between professionals (FGA: Sophia L514). Learning was also inhibited when the workshop created fear among two participants who preferred learning communication in the CLE:

Joan: 'The problem with those sessions on breaking bad news is that they say to us 'Do not do it if you are not ready.' It is such a big thing, if you do something wrong and lie to people. It just freaks you out... Sometimes it is best just not to know and then face things as they come up when you are on placement rather than being in a session making it a huge issue' (FBC: L910-915).

This raises one of the challenges of teaching, as it is very difficult to know how a workshop or lecture is interpreted. For some it may cause fear, for others a useful guide. Learning may occur in the CLE where there is not always time to practice possible responses to questions as suggested by the request for a simulation with communication training. This also suggested a theory-practice gap as communication with distressed patients was explored during the second year, but P-RNs are faced with distressed patients during clinical placements in the first year. Learning in the CLE is explored through the RM/Ms communication with relatives and patients.

*Property: Prepared for conversations versus unprepared in the CLE*

Where death occurred more frequently, for example, ITU, A&E, hospice and cystic fibrosis units, the environments were more prepared with dedicated rooms for difficult conversation with relatives as Katy and Erin explain:

Katy: 'Intensive care because death happens a lot more, people [relatives] could be taken to the room for some quiet time. Then you prepare the body and they can come back. The whole process flowed, whereas, in a ward it is bit more difficult because you cannot do that' (FGC: L193-196).

Erin 'The ITU team handled it very well. It is a wonderful place to go to learn about the management of these patients and more importantly their families' (FGA: L283-289).

In ITU the communication process 'flowed' suggesting it was without problems. In contrast wards without dedicated rooms, resulted in relatives being left in the 'communal patients day room with people coming and going' (FGC: Joan L130) and the 'ward routine proceeded around them' (FGA: Erin L579). These examples reveal the challenges of an environment that inhibits conversations and may inhibit learning sensitive communication.

Participants across the three groups explored the allocation of a single room. In the cystic fibrosis unit, ITU and hospice, RNs routinely conversed with patients in the single room, which created privacy (FGB: Rose L549; FGC: Joan L533-543). In general wards patients were offered single rooms if available, when they were expected to die, to circumnavigate restrictive visiting hours and provide privacy for the patient and family (FGA: Sophia L30-33; Olivia L51-53; Emily L54; FGB: Isabelle L47-50; Anna L52-53; FGC: Joan L39-41; Katy L106). However, participants spoke of patients refusing single rooms as they felt

'isolated without anyone to talk to' (FGA: Emily L49-59), 'neglected' or 'alone' (FGA: Olivia L51-53; FGB: Daisy L57). For some participants, single rooms became a physical barrier to communication as in this discussion between Rose and Amy:

Rose: 'In the general wards there was a gentleman in a single room with his family. To my knowledge they were just given space by the nurses. Maybe that was what they [the family] wanted. I do not know... but I felt like it would be quite nice to go to see them. It just seemed that the door was closed and I did not know what was going on.'

Amy: 'Then at meal times is it right to go in there?'

Rose: 'Yea, I found that a bit difficult actually as the ward nurses did not know the best way to approach it...' (FGB: L354-362).

The closed door seemed to be a barrier to communication; this contrasts with the hospice, ITU and cystic fibrosis units where single rooms were the norm that provided opportunities for compassionate discussions. In addition, patients who refused a single room appeared to be afraid of being ignored. Single rooms were also seen as a way of protecting other patients from the distress of seeing someone deteriorate, die and the relatives' grief:

Daisy: 'She was getting very ill towards the end, you could sense it impacting upon other patients. So you have to be sensitive to that' (FGB: L57-62).

Katy: 'A lady in a four bed bay died...there had been a lot of wailing which had obviously upset other people, so there was all that to manage as well. So all of a sudden it became almost like telling the family off which was a really awful situation...They were all just standing around... one of the sons was banging his head against the wall...almost like a trance' (FGC: 133-158).

It is evident that these are distressing and challenging situations for the P-RNs who do not know how to respond sensitively to support the family and other patients.

Subcategory: Learning to communicate with the dying and their relatives.

Registered nurse/mentor enhances versus inhibits learning communication

*Property: Registered nurse RM/Ms' strategies that enhance learning  
compassionate communication*

Participants were asked 'How do you learn to communicate with relatives and patients?' Across the three focus groups, participants observed exceptional RM/Ms who saw EOLC as an opportunity for sensitive communication with patients/relatives. Moreover, RM/Ms had developed strategies to manage their emotions so as to be sensitive without being overwhelmed during these interactions. Some of these were Clinical Nurse Specialists (CNS) (FGB: Amy L297; Rose L507; Isabelle L577; FGC: Joan L699-673), or nurses who worked in a cystic fibrosis unit (FGC: Joan L540-557), medical wards (FGB: Isabelle L367; Amy L375; FGC: Katy L74), care of the elderly (FGC: Joan L251), oncology (FGA: Erin L161), A&E (FGA: Daisy L178; Emily L279; Sophia L317; FGC: Joan L588) and ICU (FGA: David L278; Erin L286; FGC: Katy L130). Where, some were described as very experienced others were young or newly qualified (FGC: Joan L351; Katy L668). Many participants aspired to emulate these exceptional RM/Ms' management of their emotions and their sensitive communication skills:

Joan 'I learned with long term conditions there are two aspects. You get the staff who are used to the fact it will result in death and so they protect themselves. The other staff would get involved and get attached to the patient but still protect themselves but not in a detached way' (FGC: L554-557).

Exceptional RM/Ms enhanced learning by finding opportunities for P-RNs to observe doctors perceived as being sensitive when breaking bad news. Participants observed doctors in OPD (FGB: Anna L320-240), A&E (FGC: Joan L603), ward (FGC: Katy L352), ITU (FGA: Erin L286), and a hospice (FGB: Rose L302) across all three years of the programme. Learning was enhanced by observing how doctors plan for a conversation by collecting relevant information before meeting them in a private room. From these interactions, participants described learning the importance of discovering patients/relatives understanding at the beginning of the conversation. Also, using language the patient/relative could understand and ending the conversation with a plan or strategy for care were also seen as important:

Anna: 'The nurses said it would be interesting for me to have the full experience of clinic and that is why I went with the doctor... The doctor said to the patient 'What do you think is the problem?' She tried to get the patient to say what is wrong but he was not going for it. In the end he asked have I got AIDS. So I think that was his biggest fear. She said no and she dealt with it very well... She used language that you could tell he could understand... I thought it was very interesting as a first year to see the way she talked to the patient and was very caring' (FGB: L318-340).

Participants described their learning being enhanced by exceptional RM/Ms who wanted to share their expertise and knowledge. CNSs and palliative care nurses visited the CLE and encouraged the P-RNs to observe their conversations as in this example from David. Before starting the BSc programme David had completed communication training as a volunteer, and had experience of talking with the dying. In this situation David was observing a Transplant Nurse in Neurological ITU:

David: 'It was learning family involvement and the importance of that... talking to them and being honest with them. That was the biggest help for me as I had no idea before. I was terrified of speaking to them in case they asked you something.'

Moderator: How did you learn to talk with the family?

David: 'The nurse demonstrated communication there really well. Then myself being proactive in asking questions about why they say this bit and not that bit and how they said it. After seeing her talk to the family she would talk to me about how she went about doing her job. Some of the techniques and the ways she talked to them. Then having the opportunity under supervision to do some sitting and talking with the family, was so much more than head knowledge or a lecture, it was through experiencing the hard stuff' (FGA: L269-286).

The phrases 'terrified' and 'experiencing the hard stuff' encapsulate the difficulties and dilemmas faced by P-RNs when communicating with relatives during traumatic situations. Learning appears to have been enhanced by the Transplant Nurse articulating the tacit knowledge drawn upon to manage these challenging conversations. Hence, the opportunity to practice communication in the real world with feedback appeared to create a meaningful learning experience. David was fortunate to have this opportunity which seems to have facilitated a deeper understanding of how the theories of interpersonal communication skills are applied in the CLE. This opportunity appears to have built self-efficacy as David moved from being 'terrified' to being able to talk with relatives and use a personal model of communication in future conversations.

Learning was enhanced when RM/Ms praised participants' communication skills. Rose described a situation during a four week elective placement in a hospice as a second year nursing student. During this time she developed a relationship over several days with a lady who was dying and her daughter. Following the mother's death Rose found the daughter in the corridor and demonstrated sensitive non-verbal communication that was valued by her mentor:

Rose: 'Her daughter came out of the room and I just happened to be walking past. I did not have to say anything. I just gave her a look and she gave me a hug. She did not want to say anything, she just wanted us to know that we knew she was suffering and we were there. My mentor saw it and gave me positive feedback. That gave me more confidence in communication' (FGB: L550-554).

Rose was fortunate to have an exceptional mentor in a culture that promotes sensitive communication between healthcare professionals, patients and relatives. Rose also had a wealth of previous experience to draw upon as an HCA and by observing doctors and nurses' communications with patients and relatives in the hospice. She seems to have drawn upon this knowledge to communicate empathetically with this distressed relative. Consequently the praise encouraged self-efficacy to repeat sensitive communication.

Providing sensitive communication also involves managing the emotional impact of caring for the dying and their relatives. Exceptional mentors identified by different participants from various settings, ITU (FGA: Erin L171), hospices (FGB: Rose L303) and cystic fibrosis units (FGC: Joan L536-542), openly acknowledged the emotional impact that underpins interpersonal interactions by talking to and remembering patients. Participants appeared to find mentors who shared their coping strategies with them enhanced their learning to manage emotions and to talk sensitively with patients and relatives.

*Property: Registered nurse RM/Ms' strategies that inhibit learning  
compassionate communication*

Participants with and without previous experiences caring for the dying described RNs who were 'hardened' (FGA: Emily L135, David L142) or 'robotic' (FGC: Joan L517-525; Katy L526), who provided physical care but avoided talking with patients and relatives. Consequently working with these hardened robotic mentors inhibited P-RNs learning. Participants across the three groups

suggested a range of reasons for this. Sometimes the patient was receiving the LCP so 'certain wards have the attitude of don't bother to go in there he is in on the LCP' (FGC: Joan L511; Katy L514), or did not understand how to 'implement and review LCP' (FGB: Daisy L483; Amy L487). Alternative suggestions included the RN, 'not wishing to interfere with the relative's time with the patient' (FGB: Isabelle L343; Daisy L350; Rose L357) or that they 'might not be comfortable talking about death as it is taboo' (FGA: Olivia L423; FGB: Isabelle L346; Rose L361), 'difficult on busy wards to give the care that you really want to give' (FGB: Isabelle L346; Rose L391; Daisy L405; FGC: Joan L513), the patient was 'isolated in a single room' (FGA: Emily L58; FGB: Isabelle L344; Rose L357). This suggests the theory of EOLC explored in the HEI does not always match the care delivered in the CLE. A consistent worry among participants was that they would avoid patients and relatives when they become RNs as evident in this conversation between two friends in the same trust:

Joan: 'I have seen other members of staff react to death in a completely robotic way that it actually scares me that I will end up like that one day...it still affects you, it is still a life.'

Katy: So somehow you want to stay in the middle and be caring but do not want to burst into tears and encroaching upon someone's grief' (FGC: L517-527).

Robotic is a powerful metaphor. The Oxford English Dictionary Online (2014) defines robotic as 'mechanical, emotionless.' Thus, robotic nurses may be interpreted as non-human, performing tasks mechanically without feelings. 'Hardened' is defined as 'made unfeeling, callous, or cynical by experience' (Oxford English Dictionary Online 2014) suggesting the nurse is uncaring or insensitive to patients and relatives. Participants may imitate the sensitive communication techniques used by experienced exceptional RM/Ms. Participants also worried that some P-RNs may not distinguish between poor, average and excellent communication and imitate the avoidance techniques which might inhibit learning to communicate sensitively.

Learning was also inhibited when participants were not allowed to observe communication between nurses and relatives. This created frustration, as they did not feel valued as learners. This is highlighted by Emily, who is sensitive to the importance of excellent communication following her experiences as a relative:



Emily: 'I just wanted to go in with one of the nurses to listen to how she broke bad news. I do not know why but she did not let me. I thought how am I going to learn if I do not experience this' (FGA: L544-547).

Although it is unknown why Emily was excluded, potential reasons might be that the mentor may not recognise the learning opportunity, or believe it was an unsuitable situation for the participant to observe. Alternatively, the mentor may not have felt confident enough to be observed.

Learning was also inhibited by a lack of guidance on how to respond to patients' questions. Some mentors in the CLE did not appear to give advice or gave advice that conflicted with the participants' personal values. Several participants complained of conflicting advice about what to say to other patients when someone dies (FGB: Rose L407; Isabelle L413; Daisy L420-428; Anna L429). Daisy had not received any advice about how to respond to other patients questions so used her intuition. However, the mentor did not agree with her reply:

Daisy: 'A patient asked me if another patient had died and I said 'yes.' The nurse said that what she would do is say "They are unwell" and no more than that, as you should never tell them that someone else has died. I felt it was ok to say the truth. It was obvious from the commotion so I did not see any benefit to say they were unwell. But it was not my place to say that' (FGB: L420-428).

Daisy recognised the importance of supporting the other patients but seemed to be let down by the lack of guidance. In contrast, the mentor seemed to be avoiding death, this may be due to being afraid or embarrassed when confronting death in a hospital which aims to heal people. The assumption that other patients need protecting may inhibit the acknowledgement of death, and promote inconsistent practice. Daisy felt unable to question this response. This may be due to the unequal power in this relationship leaving Daisy appearing to accept the RN's advice whilst covertly disagreeing. P-RNs progress by a variety of clinical placements which require them to fit in and be accepted by mentors who are responsible for completing their clinical assessment documents. Therefore, P-RNs may not always question practices they disagree with.

Subcategory: Learning to communicate with the dying and their relatives.

Pre-registration nurses' characteristics and strategies that enhance or inhibit learning

*Property: Younger versus older and previous experience versus no previous experience of EOLC*

All participants identified the need to develop sensitive communication with patients and relatives. Older P-RNs drew upon prior experiences as a HCA or communication training to ask questions and motivate learning at the side of an exceptional RM/M (FGA: David L228; Sophia L510; FGB: Rose L507).

Participants also suggested personal experiences of grief may contribute to an understanding of the importance of sensitive communication to help patients and relatives understand and come to terms with a death (FGA: Erin L115; Emily L188-197; FGB: Isabelle L241; FGC: Katy L188). Nurses may meet relatives only once, as highlighted by Emily who, as a relative encountered an exceptional RM/M who inspired her to become a nurse and develop her communication skills:

Emily: 'My grandfather passed away very suddenly. When I went into the A&E a nurse took me aside. I was 16 and she explained to me in very simple terms what was happening, what was going to happen and what that situation looked like from my perspective. I thought that was very important to explain that to a young adult in terms that they understood because that could be daunting. If that had not happened, I would not be sat here or got over it in the way I did' (FGA: L188-197).

Although, older P-RNs may have more life experiences to draw upon when learning communication skills; experiencing grief at any age may also promote learning and enhance insight. Therefore prior experiences rather than age appeared to have influenced learning to communicate.

P-RNs with previous experiences as an HCA had learned to manage the emotional impact of dying and death by postponing their emotions until later (FGA: Sophia L137; FGB: Rose L227). In contrast, some participants with or without personal experiences of caring for their relatives, were initially overwhelmed emotionally, and unable to communicate. These participants then learned how to delay their emotions as they progressed through the programme (FGA: Emily L145; Olivia L152; Erin L159; FGB: Daisy L255-269; Amy L270; FGC: Katy L70; Joan L310). This is evidenced by Katy whose parent died before she commenced the programme:

Katy: 'It seems awful that somehow the first experience that you might cry and that may be acceptable, but then the second time you are not going to cry...As the daughter came to me, I could feel my tears well up as she was speaking to me. Obviously this was her grief, not mine,

but my voice was shaking. So my mentor came over and was absolutely lovely .... Afterwards I said to my mentor I have so much respect for you as your voice did not crack, you were very calm. As she said, unfortunately it is something you get used to... When I worked in ITU [second year]...his wife and son came to thank everyone... she held my hand and looked into my eyes. I thought I might cry and I did not... We had a really nice discussion. I thought well I did learn from that previous experience. I can look into somebody's eyes and I can feel empathy without breaking down and crying. You think that is just showing how you can harden yourself to the experience. Is that a good thing?' (FGC: L68-89).

Katy's experience reveals how these conversations are emotionally charged as P-RNs form a bond with relatives and patients. She learned to manage her emotions by consciously facing up to her discomfort. Katy did not talk about flashbacks to personal experiences when her parent died but describes being empathetic. Her learning was enhanced by an exceptional RM/M who appears to have valued Katy in a sensitive way when she was too upset to talk. Being valued appeared to contribute to developing an emotional maturity that allowed her to remain sensitive while protecting herself from some of the emotional impact.

*Property: Self-directed learning to communicate with the dying and their relatives*

A consistent comment was that participants felt unprepared when talking with patients and relatives. Olivia explains:

'Personally I think first thing is you do not want to offend anyone, they may remember something distinctly in a time when they are grieving you do not want to alter a grieving process for the worse' (FGA: L542-543).

Participants instigated opportunities to learn sensitive communication techniques. Participants from all three focus groups mentioned creating personal learning objectives aimed at improving communication skills (FGA: David L273; Erin L285; FGB: Rose L302). A key learning strategy was seeking out and observing exceptional RM/Ms who they perceived as good communicators (FGA: David L273; FGB: Amy L295; Rose L305; Isabelle L578; FGC: Katy L658) and testing their communication skills by intuition/trial and error (FGB: Rose L546; Isabelle L566; Amy L652). These emerged from participants of all ages who had, and had no prior experience caring for the dying.

Katy described how learning was enhanced by covertly listening to a RM/M. A patient had received a diagnosis of cancer in a ward bay with three other patients nearby. The patient and her husband were upset so the curtains were drawn around the bed area to provide privacy. Katy offered cups of tea but she felt guilty as she did not know what to say:

Katy: 'I felt really bad... I was trying to be supportive, they were not ready to talk so it was 'would you like a cup of tea?' or 'Shall I get you anything?' I think the nurse I was working with that afternoon was not good at those situations. But the following morning I was working with this really lovely nurse... I explained about this lady. She was a newly qualified nurse and asked to spend some time with the patient, unless I wanted that experience. I said no that is fine. I learned so much, the curtains were drawn and the nurse was talking in a quiet tone, but I was listening while I was with the other three people in that bay. I said to her afterwards, I learned a lot from that I am really impressed about the way you dealt with that situation' (FGC: L658-720).

This exemplar reveals how P-RNs may be faced with distressed patients and relatives and the emotional impact of not knowing how to respond with compassionate language. Katy was fortunate to be able to covertly listen to this exceptional RN to learn for future encounters. Hence RM/Ms may be unaware they are teaching during their conversations. This is also a reminder of how the lack of privacy to discuss intimate issues is a challenge for patients, relatives and professionals.

In response to the limited guidance on how to respond to challenging conversations, participants spoke of instigating learning by 'trial and error' (FGB: Isabelle L566; Amy L652). As a consequence, Amy's learning was inhibited as she was unprepared for answering challenging and unexpected questions. She had no previous experience as an HCA to draw upon and while washing her patient in her third year was placed into a dilemma that she did not know how to respond to as in this conversation:

Rose: 'I don't know we have not really said anything about when the patient says "Am I dying?" and what we do then. I normally sit and just say "What makes you feel that?" and go through that with them. I am never sure if that is the right thing to do or not. You cannot really say "no" or "yes." So I tend to turn it back on them and try to get them to think about why they think that. I get someone more senior to see them if I cannot cope with the situation myself. I do not know if it is something that you can teach or if it is something you can only do if you experience it?'

Amy: 'I have had a patient say to me "I have only three months to live." It was casually while I was getting a bowl ready for their wash. That throws me off guard and I do not know what to say. The patient was obviously willing to talk about it but it was me that did not know what to say. I have spoken to people afterwards and asked what should I have said and I have never found an answer that I feel comfortable with. Trying to say well "I am going to make them as comfortable as possible" makes it sound like they are going to drop dead tomorrow and you do not want to highlight the fact they are going to die, although that is what they are talking about'

Daisy: 'May be "How you are feeling about it?" Perhaps I do not know I have not had that situation. It is difficult really difficult.'

Amy: 'I think when you enter a conversation you are expecting it to be difficult you're arming yourself. But when you pick up the phone and it is a relative talking, or you just walk into a room and the patient's in tears, suddenly you have to bring in all these skills.'

Daisy: 'And it is not every day that you have that.'

Amy: 'Not at all.'

Isabelle: 'It takes you off guard.'

[Silence]

Moderator: 'What were the suggested responses?'

Amy: 'Some said to sit down and ask "How do you feel about that?" or "Is there anything I can do for you?" but the patient said this more as a casual statement, so I did not know if I should respond in a formal way or if she wanted to discuss it... I offered a cup of tea. It is my way of saying I care about you and often actually it is quite successful as it gives them time to compose themselves. I think if they are upset, you do not have to be sitting there talking, they may want to be alone for a while to think. It gives me time to think what to say' (FGB: L615-659).

This example illustrates how Rose stimulated the group discussion in which Amy reflects upon her experience of responding to a challenging conversation. During this conversation participants shared prior knowledge and uncertainty with Amy and although different suggestions were made, they seemed unsure as to whether their responses were effective. The accounts from the other participants elaborate their prior knowledge and expand on their views of how to respond. This shared co-construction leads to an understanding of the lack of consistent advice and guidance given to P-RNs in responding to difficult conversations. Amy seemed disappointed by her lack of skill in knowing how to respond to this challenging conversation. Although she had cared for the dying in medical and surgical wards she had no opportunities to observe RM/MS

responding to challenging conversations in ITU, A&E, oncology or hospice settings. Amy did not feel comfortable talking about dying and described 'arming yourself' when the conversation is expected to be difficult. This is a powerful analogy with protection against injury in a battle. This lack of training in communication has left Amy without the techniques to protect herself from the emotional impact and enable her to respond sensitively to the patient. As a result she appeared shocked and uncertain as to how to respond and created distance in order to decide how to reply. A further issue is that it is unclear what the patient expected, however this intimate interaction appears to encourage this patient to talk. Indeed participants explained that 'students can be there for the family as you are supernumerary' (FGC: Joan L513) so the P-RNs 'give good quality of care,' (FGB: Isabelle L364). However, this can be distressing for a student who has not been prepared with examples of how to respond. Yet P-RNs are expected to know how to reply, therefore, it would seem pertinent for mentors and HEIs to prepare P-RNs with suitable responses.

Joan had a similar experience to Amy. Like Amy, Joan did not have prior experience as an HCA or caring for relatives and was unsure of how to respond initially. However, in this example as a third year P-RN she had developed confidence in responding to challenging conversations. Joan described learning from exceptional RM/Ms, her experiences of talking with patients and relatives and she also attended the communication workshop in the HEI. These experiences seem to have been utilised to respond to a very challenging conversation in a sensitive empathetic manner. This example was with a patient in a surgical ward who had been diagnosed with cancer:

Joan: 'I was the next one to go into the bay and she burst into tears... I had a chat with her and just tried to reassure her that she had not had all the information yet. Because I knew at this point the doctors had just seen her. I asked if she had seen the bowel cancer nurse specialist and she said she had not. So I called him and he came up that afternoon. I asked if I could sit in on the conversation and see how he would talk to patients who had been newly diagnosed, which was a really good learning experience. He talked with her, explained all the physiological side of things, gave her contacts of places she could get help and answered all her questions... He was brilliant because the tone of his voice seemed to be reassuring and calming. I think for someone who was highly strung that was the best person to talk with her. It was a valuable experience because I was there from the start and supported her. I did not give her advice but was a shoulder for her to cry on. Then I got someone there who knew everything. The CNS

showed me how to talk to someone who had been newly diagnosed with cancer. So that was the perfect scenario as a learning experience' (FGC: L614-715).

Joan undertook a very difficult, complex discussion with sensitivity and compassion. She did not block the conversation but acknowledged the patient's concerns, assessed her understanding and acted as an advocate by contacting the CNS. She then maximised her learning by observing the conversation between the CNS and patient, noting the mannerisms and responses to questions. This appeared to be incorporated into her model for future conversations. This conversation is striking as it reveals how Joan gained in confidence and developed a variety of valuable communication techniques over time. Although it was unclear if she received any feedback from the mentor that might reinforce this sensitive behaviour, there is a sense of personal achievement and self-efficacy. Many participants described seeking out and observing exceptional RM/Ms then imitating their communication techniques in their conversations. As Isabelle explains:

Isabelle: 'You find yourself adopting the same kind of tone and the way they talk and I think, "Am I imitating you a bit?" They have a calm mannerism the way they hold themselves and talk and sit, giving the patient enough time' (FGB: L572-574).

These thoughtful and sensitive interactions by exceptional RM/Ms seem to have helped this participant recognise the subtleties of communication. Thus learning a response to unexpected challenging questions was perceived as less stressful than not knowing what to say.

### **Category: Learning to perform last offices**

Participants divided into two clusters, those who had performed last offices as a HCA before commencing the programme and those who had not. This category explored how participants learned to perform last offices.

#### Subcategory: Learning to perform last offices. Context of learning in HEI versus CLE

*Property: Theory of performing last offices in the HEI*

Participant's described how learning to perform last offices was 'left to a mentor in the clinical area' (FGB: Rose L447). Participants who had not performed last offices before the programme consistently requested a session before the first clinical placement about what to expect when people die. Suggestions included

the 'physical signs of death and body fluids' (FGA: Emily L402; Erin L410; FGC: Joan L895), 'performing last offices' (FGA: Emily L402; FGB: Isabelle L92; Rose L94; FGC: Katy L886; Joan L892), 'talking to the deceased' (FGA: Sophia L362); 'using a shroud' (FGC: Katy L882), 'recording their property' (FGA: Emily L402) and 'transporting the deceased from the ward' (FGC: Katy L903). This seems pertinent as P-RNs may perform last offices during their first placement (Table 5.4).

One of the strengths of learning in the HEI is the opportunity for students to share their learning strategies in the lecturer-facilitated smaller groups.

Sophia: 'In the Adult Complex Needs module...we were talking about last offices and I was surprised that I am not the only person in the world that actually talks to my patients when I am carrying out last offices' (FGA: L363-366).

Sophia: 'I think it helps that our lecturers are experienced so you can sit down and just talk it through' (FGA: L382-783).

In contrast, it is difficult to explore individuals' concerns in a lecture. However, RNs in the CLE may be able to deliver a more individual approach. This sharing also reveals the dichotomy of learning the theory in the HEI and the importance of the mentor to facilitate its transfer by role modelling in the CLE.

#### *Property: Performing last offices in the CLE*

Performing last offices were described as treating the person with dignity and respect irrespective of the context of a residential care home (FGB: Rose L227), hospice (FGB: Rose L126), medical ward (FGA: Sophia L32; Olivia L580; FGB: Erin L496; Amy L556; FGC: Joan L34), A&E (FGA: Emily L196) and ITU (FGC: Katy L126). For Daisy resuscitation attempts in A&E were viewed as 'undignified', so that last offices were an opportunity to show the respect to that individual:

Daisy: 'Afterwards doing last offices' with the RN who was fantastic. It was dignified and we made it really nice for that lady' (FGB: L99-104).

This suggests that dignity and respect to the deceased person is embedded in nursing culture and that the RM/M was the key figure guiding their learning to manage the skill and their emotions.



Subcategory: Learning to perform last offices. Registered nurse/mentors' strategies that enhance versus inhibits learning

*Property: No opportunity to practice last offices, RM/M did not explain procedure or provide guided reflection*

Participants described how RM/Ms' attitudes to P-RNs enhanced or inhibited learning to perform last offices. There were a few examples of learning being inhibited by mentors excluding participants from last offices. Participants reasoned that this might be due to mentors 'protecting us from a traumatic situation' (FGB: Rose L107). Alternatively, the mentor may not have the expertise to support the P-RN during last offices. A rarer example was a participant not being guided during last offices or reflection to explore the procedure and the emotional impact. Joan's vivid account below deepens the understanding of the emotional impact of performing last offices and properties that inhibit learning. At the time Joan was 18/19 years old and on her first clinical placement. Furthermore, Joan was feeling sleep deprived during a night shift:

'That HCA did not do it particularly well... A lot of things happened that I was not expecting. There were a lot of body fluids coming out of every orifice and the smell! I literally felt ill and went out and vomited. But I came back because I thought I might as well face my fears. I found it a bit shocking. I was not having a very good experience either. I was just emotionally and physically drained.'

Moderator: 'Did you have support?'

Joan: 'One of the nurses asked me if I had learned from it as a comment in conversation rather than being supportive. I said it was a bit horrible and I was not feeling very well. She said "sometimes it does get to you." So I did not get support that first time or talk with a nurse. I tended to talk to other students like Katy [Katy smiled supportively towards Joan]' (FGC: L325-345).

Learning to perform last offices was inhibited as Joan did not appear to be valued as an individual by the HCA or RN. There does not appear to be any explanation of the procedure or why there were body fluids and there does not appear to be any compassion for Joan. This does not seem to promote a feeling of belonging to the ward team. Indeed, Joan says that she was 'having a bad time' (FGC: L348). She explains the absence of a ward manager resulted in power struggles between the RNs, so there did not appear to be a coherent team approach or culture of guided

reflection/debrief. Another explanation is that HCAs do not receive training to facilitate P-RNs learning.

*Property: RM/M explains procedure and provides guided reflection*

In contrast, there were many examples of participants' learning being enhanced by an exceptional RM/M (FGA: Sophie L32; Erin 496; Emily L196; Olivia L580; FGB: Rose L227; Erin L496; Amy L556; FGC: Joan L340-354). These exceptional RM/M treated the deceased person with dignity and respect during last offices and explained the procedure to the P-RN while performing last offices. The P-RN was valued as an individual with an opportunity for guided reflection to explore their feelings and learning for future last offices. Joan's second experience was with a nurse who encapsulates the characteristics of an exceptional mentor:

Joan: 'It was really dignified and it was with a nurse who was very good with the patients. At the end she literally went through it with me, asked "How are you feeling about this?" We were both talking to the patient at the same time during last offices. She asked me if I was comfortable with that and if I would have done that if I was by myself. She was a very young nurse and she sat with me for 15 minutes and went through it. We did talk about my previous experience and made comparisons. She gave me advice for the future. She explained what had happened that first time in terms of body fluids' (FGC: L340-354).

Joan learned because in contrast to the first experience this exceptional RM/M made a connection with her by valuing her as an individual learner and recognising the potential emotional impact. She was compassionate, allowing Joan to talk about her previous experiences and explaining the physiological changes, thus enabling learning for the future.

The mentor enhanced Joan's learning by explaining the procedure during last offices. Although, there did not appear to be an opportunity to repeat last offices with this mentor, Joan identified that there had been no problems undertaking last offices after this discussion. This suggested Joan had learned the skill of performing last offices and techniques to manage the emotional impact. A contributing factor may be the mentor's age which Joan described as 'young.' So it may be postulated that she remembers her experiences as a P-RN and consequently is more in tune with their learning needs. Another possible outcome from this second encounter is the behaviour of the exceptional mentor may be imitated by the P-RN as a RN, supporting students in the future. Hence,

the mentor is a key component in the dichotomy between inhibited and enhanced learning in the core category.

Subcategory: Pre-registration nurses characteristics that enhances versus inhibits learning to perform last offices

*Property: Younger versus older participants and previous experiences performing last offices versus no experiences of last offices*

Crucial elements that enhanced and inhibited learning to perform last offices were P-RNs age and previous experiences as an HCA. Participants divided into two clusters, those who had performed last offices before the programme as a HCA in a residential care home and those who performed last offices for the first time during the programme. It is possible that participants who were younger without previous experience may have found learning to perform last offices more inhibiting than those who were older with possibly more experience of death among family or friends. However, their comments suggest that learning is enhanced or inhibited by the mentor rather than by age. Rose sheds light upon her first experience in a residential care home and how this influenced her first clinical placement:

Rose: 'She was the first person I saw dead. It was dealt with very well. The Matron came with me, I did have a wobble, it was OK... I think if I had gone into my nurse training without that experience it would have been more difficult. I did have quite a few deaths on the first placement. I put a lot of pressure on myself and expect to cope' (FGB: L227-232).

Exceptional RM/Ms were sensitive to the possible emotional impact of seeing a dead person, which enhanced the participants learning. This participant drew upon her previous experiences as an HCA to perform last offices. For Rose this experience created higher self-expectations, although the role of the P-RNs is different to that of an HCA. This perspective should be interpreted with caution as it is possible that mentors expect greater skills, knowledge and emotional maturity from a former HCA than a P-RN without this experience. In this situation, Rose was valued as an individual and offered guided reflection/debrief following CPR and in a hospice experience.

*Property: Self-directed learning to perform last offices.*

Participants without previous experience in last offices were highly motivated to learn. A widespread concern was qualifying without this experience and being

expected to teach P-RNs (FGA: Sophia L38; Olivia L359; Erin L581; FGB: Rose L105; Anna L110; Isabelle L495; Daisy L501; Amy L502; FGC: Joan L351; Katy L598). Self-directed behaviours included creating personal learning objectives (FGC: Katy L114) and seeking opportunities to perform last offices (FGC: Katy L115; Joan L351). One particularly helpful strategy was reading how to perform last offices in preparation (FGB: Isabelle L495-498). However, learning may be inhibited if these strategies are not initiated.

Participants shared their differing perspectives on performing last offices and illustrated a feeling that death is a time to show dignity and respect by the seriousness underpinning washing the individual. Participants seemed to develop a set of coping strategies for performing last offices. Observing the dignified attitude of mentors and understanding the signs of death contributed to developing a personal set of values that encompassed performing last offices with dignity and respect until they left the ward:

Daisy: In A&E, CPR is undignified... Afterwards doing the last offices, I did have a good experience with the nurse I was working with who was fantastic and we did that together. It was quite dignified actually we made it really nice for the lady' (FGB: L100-104).

Talking to the deceased person during last offices was considered by some to be showing dignity and respect and helped some cope with the procedure:

Sophia: 'We were talking about last offices and I was surprised that I am not the only person in the world that actually talks to my patients when I am carrying out last offices as if they are still there.'

Olivia: 'I think it is a sign of respect to say "Hello Mrs Smith I am going to roll you over and give you as wash to freshen you up." I think that has been instilled in us, that dignity and respect has been a huge and valuable part of our training from the university. I think as a student nurse you take that forward'

Emily: 'I do not think it is wrong at all, I completely understand, and I hear what you are saying about respect and dignity. But personally I cannot bring myself to talk to them... But I do not think it is wrong that you don't.'

David: 'I do not.'

Sophia: 'Caring for a dying person is very personal' (FGA: L366-379).

For Sophia and Olivia this was the same as when the person was alive by talking and handling the body carefully. Emily and David did not speak to the deceased suggesting that for these P-RNs whilst the dead body has ceased to be an individual, it still needs to be treated with respect. This process of elaborating and co-constructing their knowledge included respect for each other's differing coping strategies. For some, performing last offices helped 'achieve closure' (FGA: Emily L201) and was 'rewarding...a privilege' (FGB: Rose L107; FGC: Katy L979). Following last offices participants used the same strategies to manage their emotions outlined in 'Learning to manage expected and unexpected deaths.' These included personal reflection, demarcating between family and home and reflecting with nursing friends.

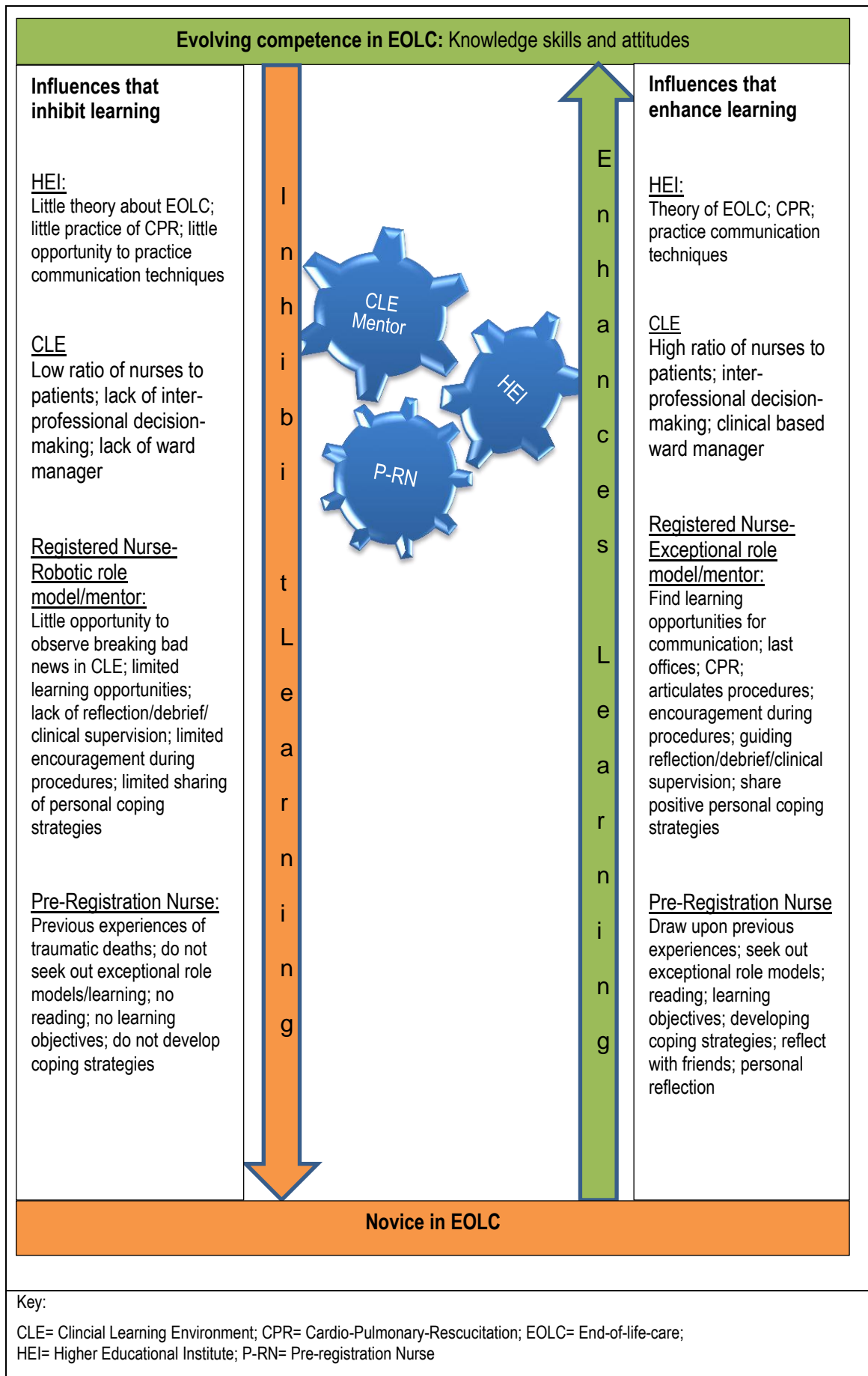
### **Synthesis of factors that enhance and inhibit pre-registration nurses learning end-of-life-care**

This section draws together the findings into a conceptual map to demonstrate the relationships between categories and subcategories in the data (Figure 5.1). In my study, learning EOLC comprised managing expected and unexpected deaths, communicating with patients and relatives, performing last offices and CPR. Each death was a 'different experience,' (FGB: Rose L141; FGC: Joan L986). As depicted in the conceptual model, learning does not appear to be a linear or sequential event where each experience automatically builds on another and creates competence. The P-RN may oscillate between being a novice in EOLC and evolving competence in EOLC. The concept of novice was selected based upon Benner's (1984, 2004) description of the novice stage of skills acquisition being

'areas on which the student has no experiential background to base an understanding of the clinical situation' (Benner 2004 p191).

It may be the first time seeing a person who has died, performing last offices or experiencing a traumatic or unexpected death. A novice in EOLC has not developed the knowledge, emotional self-management or skills to care for the dying and their relatives. P-RNs experience may be influenced by not having developed the communication skills and knowledge base to respond to patients' and relatives' difficult questions (Figure 5.1).

Figure 5.1 Factors that enhance and inhibit learning EOLC: a conceptual map



The term evolving competence was selected based on the work of Eraut (1994) who defined this as:

'being able to perform the tasks and roles required to the expected standard.' (Eraut 2012 p12).

Evolving competence in EOLC, relates to learning psychomotor skills, knowledge and emotional self-management. P-RNs develop the confidence, interpersonal skills and knowledge to respond to patients' and relatives' challenging questions in a sensitive manner. As a result, a professional level of care is delivered by treating patients with dignity and respect. They act as the patients' advocate by liaising with RNs and doctors to provide physical, emotional and spiritual interventions. Underpinning this care is the ability to develop emotional self-management that allows sensitivity to patients and relatives while not being overwhelmed by their own emotions.

As every death is a unique experience, P-RNs may oscillate between being an novice and evolving competence in EOLC. They may be evolving competence, by developing some skills, knowledge and emotional management but may move towards the level of a novice when they are faced with a traumatic or new situation. For instance, a P-RN may have cared for many people who are expected to die and thus have developed communication skills and emotional self-management, but when faced with their first cardiac arrest or the death of a child may revert to being a novice. As a consequence new knowledge, skills or emotional self-management strategies are developed to return to evolving competence. It is anticipated that with a wider variety of experiences the P-RN moves towards developing competence.

P-RNs create a set of personal values which form the basis for EOLC. These appear to be drawn from personal experiences, theory of EOLC, clinical experiences, and modelling exceptional RM/Ms. The personal values include: how to act when initiating sensitive communication; providing care with dignity and respect; being a patient and relative's advocate; and learning to manage their own emotions so as to appear compassionate and not overwhelmed. In contrast, P-RNs also identified care they did not want to emulate when nurses appeared hardened and did not create learning opportunities (Robotic RM/M). These factors may inhibit P-RNs' progress towards evolving competence.

Never-the-less, the proactive P-RN may instigate learning and seek out exceptional RM/Ms to continue their move towards evolving competence.

In the HEI, theory of EOLC and sensitive communication assisted P-RNs' evolving competence in EOLC. However, when there was a gap between the sequencing of theory with practice, participants felt unprepared for death and dying. Learning alongside RNs, in environments which promoted sensitive conversations with patients and relatives, where there was inter-professional decision-making which valued the nurses' knowledge and skills and enhanced learning, so that they evolved competence. In contrast, where CLEs were poorly prepared for EOLC, combined with a lack of facilities for compassionate conversations or limited inter-professional decision-making, learning EOLC was inhibited. In addition, higher nurse to patient ratios appeared to allow greater opportunities for P-RNs to learn EOLC and practice sensitive communication alongside their mentor.

Learning EOLC is an interaction between theory and practicing skills in HEI, culture of EOLC in the CLE, RM/M and P-RNs learning strategies. These properties do not occur in isolation, but are interconnected like cogs in a machine. When these interconnections enhance learning, the P-RN moves to evolving competence in EOLC.

### **Summary**

Taken together these findings provide important insights into factors that enhance and inhibit P-RNs learning EOLC. It is evident that the HEI explores the theory and that a RM/M facilitates the P-RNs transfer of knowledge into practice by role modelling, guided reflection, praise and encouragement. P-RNs are not passive learners they seek out exceptional RM/Ms and also draw upon personal experiences. These learning experiences appear to be created into a set of personal values in EOLC. The findings also revealed a gap between the sequencing of theory and practice, and raises questions about the transfer of personal, professional and tacit knowledge into patient care. The next chapter discusses these findings in relation to theories of learning and the literature from the meta-ethnography in Chapter 3.



## Chapter 6 Discussion

### Introduction

This study set out to explore P-RNs' perceptions of how learning end-of-life-care could be enhanced in the HEI and CLE. Three categories emerged from the participants data '*Learning to manage expected and unexpected death,*' '*Learning to communicate with the dying and their relatives*' and '*Learning to perform last offices.*' The analysis revealed a complex learning relationship between the HEI, role models/mentors (RM/M) and P-RNs, that assisted P-RNs to move from being a novice to evolving competence in EOLC. The five key features of learning EOLC are the translation of knowledge in end-of-life-care; learning through role modelling; motivation to learn end-of-life-care; learning to manage the emotional labour of end-of-life-care; and promoting a safe learning environment. These important features will be discussed in relation to existing literature and theories in order to explain the findings and highlight implications for P-RNs learning in the HEI and CLE. To differentiate the findings from other literature the terms 'this thesis,' 'this investigation,' 'my findings,' 'my study,' 'this thesis' and 'participants' refer to this doctoral study.

### **Summary of the findings: Enhancing P-RNs learning knowledge and skills in end-of-life-care**

The traditional view of learning a vocational profession such as nursing is that P-RNs learn theory in the HEI and then implement it in practice via activities and experiences with RM/M in the CLE. Participants described their learning of core skills and knowledge about EOLC. These included managing expected and unexpected deaths; performing CPR; managing the emotional impact of providing EOLC; sensitively communicating with patients/relatives and performing last offices. Figure 5.1 in Chapter 5 outlines factors they identified as enhancing or inhibiting learning and reveals the novel finding that P-RNs' learning EOLC did not follow a linear trajectory in which each experience builds incrementally on the previous ones. Instead learning oscillated between being a novice in EOLC to evolving competence in EOLC. A novice P-RN has not developed the knowledge base, emotional self-management or sensitive communication skills to respond to patients' and relatives' difficult questions (Figure 5.1). Evolving competence relates to learning these skills so as to be able to respond appropriately to the dying and their relatives. However, when

P-RNs are faced with a new experience such as responding to challenging questions from patients or relatives or their first experience of cardiac arrest they are likely to revert back to being a novice.

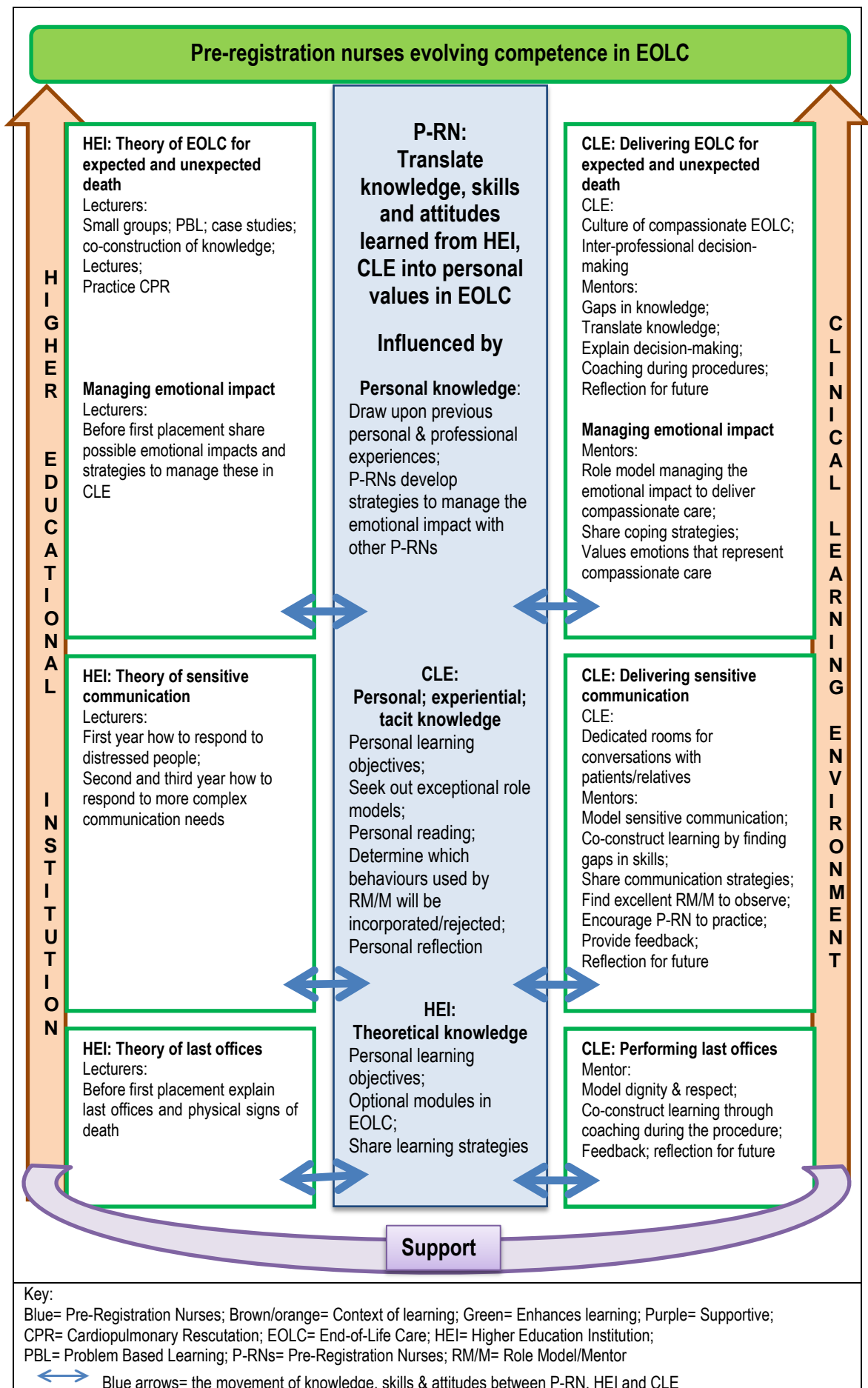
Factors that enhance P-RNs learning EOLC (Figure 6.1) were identified and explored in relation to the translation of knowledge between the P-RN, HEI and CLE. Learning occurs both within the context of the HEI and the CLE whilst being shaped by the PRNs' developing personal values about EOLC. In the HEI the focus is on learning the theory of EOLC for expected and unexpected death, managing emotions, sensitive communication and last offices. In the CLE experiential learning occurs through delivering EOLC alongside RM/Ms.

Learning the theory of EOLC or communication in HEI in year two of their programme of study did not necessarily coincide with practice-based experiences, as EOLC could occur as early as the first clinical placement, whilst for others, it happened later. Thus theoretical learning may have taken place before or after experiential learning alongside RM/Ms in the CLE and for some was perceived as a gap between theory and practice. On occasions when P-RNs theoretical and experiential learning was enhanced by working and learning collaboratively with RM/Ms, P-RNs reported that they felt they moved to evolving competence. Strategies that enhanced P-RNs learning included RM/Ms valuing the PRNs as an individual learner; responding to the emotional impact upon P-RNs; seeking out learning opportunities; sharing their knowledge and providing feedback and reflection following an event.

This method of co-construction of learning passes theory and experiential knowledge from one generation of RNs to the next. However, this is limited when the knowledge shared does not follow current evidence, or the strategies are maladaptive such as avoiding conversations with patients/relatives. In addition P-RNs' reported their learning was inhibited when RM/Ms did not recognise the emotional impact or provided limited learning and reflection/debrief/clinical supervision. Thus in these situations learning was inhibited or stalled and they regressed towards being a novice.

P-RNs were not inanimate conduits or receptacles through which learned knowledge and skills were stored unaltered for later use in the care of a patient or relative. Instead P-RNs were active learners who processed the knowledge

Figure 6.1 Factors that enhance P-RNs learning EOLC



and skills gained before and during the BSc programme into personal values of EOLC (Figure 6.1). In addition, P-RNs drew upon their prior personal experiences as a relative/HCA and P-RN, so that knowledge and skills were built upon and developed during each opportunity to practice EOLC, which they could adapt in new clinical encounters. It was this ability to adapt and translate knowledge they have learned between different clinical contexts that characterised a P-RN who was evolving competence from being a novice.

Participating in PBL case studies in the HEI or reflecting with friends who were nurses enabled P-RNs to share their knowledge and experiences they have gained. P-RNs' personal and professional knowledge and skills influenced their developing personal values about what constitutes compassionate EOLC as their experiences accrued during the programme and fed into P-RNs evolving competence in EOLC. The five key features of learning EOLC were: translation of knowledge in end-of-life-care; learning through role modelling; motivation to learn end-of-life-care; learning to manage the emotional labour of end-of-life-care; and promoting a safe learning environment, will be discussed in relation to learning theories and previous research in order to explain the findings and highlight their implications for P-RNs learning in the HEI and CLE.

### **Translation of knowledge in end-of-life-care**

P-RNs processed the theoretical knowledge and experiential learning of performing last offices, CPR and sensitive communication via their personal values to evolve competence. However, participants described the challenges of trying to make sense of the decisions and interventions made by RM/Ms related to the theory of EOLC. Consequently, P-RNs remained a novice which impaired their ability to deliver compassionate care. The following discussion explores how RM/Ms and lecturers enhance P-RNs learning by the translation of theory into the workplace to evolve competence in EOLC.

A number of theoretical models have been proposed in order to enhance understanding the principles involved in applying theory in the work place. Eraut (1985, 1994, 2000, 2004a,b, 2007a,b, 2012) has written extensively about the theory of the transfer of knowledge among RNs, implying that formal theory learned in the HEI is expected to be delivered unaltered into patient care in the CLE. Knowledge may be transferred from one person to another; one group to

another; or from one context to the next in the CLE (Eraut 2012). Eraut's (2000) work has been challenged by Spouse (1998, 2001a) as being too limiting to explain P-RNs' education. The findings in my study support Spouse's argument (1998, 2001a) that theory is not automatically transferred. Rather, knowledge is brought into use in the CLE by the expert RM/M, who supports (scaffolds) the P-RNs until they can use it independently. In addition my work supports Evans' et al (2010) notion that knowledge is re-contextualised in the HEI through programme design (content re-contextualisation); teaching methods (pedagogic re-contextualisation); the importance of the 'knowledge broker,' who is an expert who facilitates learning through interpreting it for use in the workplace (workplace re-contextualisation) and a learner who actively processes the knowledge by interpreting it for use in the workplace (learner re-contextualisation). However, importantly neither Evans et al (2010) nor Spouse (1998) explored P-RNs learning about EOLC. This investigation contributes to the understanding of the evolving competence by arguing that knowledge is translated via an individual's personal values into the skills necessary to deliver compassionate EOLC.

Eraut's (2004a) model of the transfer of knowledge proposes that previously obtained knowledge is extracted, understood in the new situation and integrated with other knowledge to guide how the person thinks and acts in the new situation. Eraut (2004a) places this into the model of 'Activities during a performance period' (p208), during which the RN reads the situation through a constant interaction between thinking, doing and complex interpersonal communications. When the patients' conditions are rapidly changing Eraut (2004b) termed this a 'hot action' context due to the continuous assessments and responses required. RNs demonstrated three types of transfer influenced by time and cognition. Firstly, an instant almost semi-conscious pattern recognition accompanied by a routinised behaviour response and secondly, a rapid/intuitive comparison to previous similar situations with a greater awareness of what one is doing. Both these occur when there is little time for reflection due to the context or the RN's expertise. Finally, a deliberative/analytic transfer is characterised by more time for thinking about previous actions and knowledge to frame the problem and process how it is being handled possibly through consultation with others. This may be due to RNs lack of knowledge or the situation requiring a more thoughtful response

such as discharge planning or selecting a wound dressing. However, Eraut (2004b) found these modes of transfer were difficult to analyse as a RN may use a combination of instant, rapid/intuitive and deliberative/analytic transfer according to the context of the patient's condition, the case load and the formal, personal, tacit and experiential knowledge available. (Eraut 1995, 2004a,b 2007a,b). In addition, Eraut (2012) explains that learning knowledge and skills for transfer as a RN is informal, sporadic and dependent upon the individual's desire to develop their own understanding. This important model reveals the complexity of the RN's role, however, in relation to pre-registration nursing this model is overly constrictive as P-RNs learning EOLC are novices without the range of knowledge and skills that RNs can draw upon. Indeed P-RNs are expected to accrue these during their BSc programme and therefore require assistance to understand and apply the knowledge and skills to provide compassionate EOLC.

In addition, Eraut (1985) drawing upon the work of Buchler (1961) argues that knowledge and skills are applied unaltered for each patient or adapted for specific situations such as communication with relatives or treatment choices. However, participants in my investigation described each death as unique, with examples of expected and unexpected death in which some patients required CPR and in addition, relatives ranged between being calm, tearful or wailing. Consequently, P-RNs reported that they needed to learn to interpret each situation within its context and decide how to respond. This could be difficult and challenging without theoretical and experiential knowledge to draw upon. In addition, nurses develop experiential knowledge termed tacit knowledge, which may be difficult to describe to the P-RN (Benner 1984, Spouse 1998). Drawing upon Broudy et al's (1964) typology of the application of theory, it appeared that an intellectual effort was required to interpret knowledge so that it can be applied into the context of nurses' professional judgement and problem solving. Translating formal and tacit knowledge was enhanced when RM/MS explained about the patient's deteriorating condition and demonstrably integrated this into compassionate EOLC. Therefore translation had two consequences: firstly to interpret theory and clinical experiences into meaningful language for the P-RNs and secondly to convert knowledge into skills for the delivery of compassionate EOLC, thereby helping P-RNs to develop their personal values of EOLC.

The traditional assumption is that the transfer of knowledge suggests that theory learned in the HEI is followed by its application in the workplace (Eruat 1985, 1994, Salomon & Perkins 1998). Although knowledge is accrued in the HEI and with each experience of EOLC (Figure 6.1), participants reported they performed EOLC, last offices and with dealt with distressed relatives prior to learning the theory of EOLC and attending communication workshops in year two. Therefore, participants were unable to draw upon theory learned in the HEI. Instead initial learning was derived from RM/Ms who shared their knowledge and skills of EOLC, sensitive communication and performing last offices. Translation was not a one-way process with the R/MM implanting their knowledge for it to be absorbed like a sponge by the P-RNs. Instead there was a co-construction of learning through P-RNs revealing gaps in their knowledge and clarifying their understanding of the procedures, communication and compassionate care with the RM/M. In addition, RM/Ms and participants reflected together after CPR, last offices and some challenging conversations. These learning conversations can be partially explained through Vygotsky's constructive social situation theory of learning which proposes that learning is contextual with social participation (Daniels 2005). The above section has introduced the notions of scaffolding support for learning and the influence of the CLE. These and the sequencing of theory and practice will now be explored.

#### Scaffolding support for learning end-of-life-care

Vygotsky and Luria's (1930) constructive social theory of the Zone of Proximal Development (ZPD) derived from observing children learn to speak a language. This theory proposes an individual is located within an inner boundary of existing knowledge (knowledge-in-use) and is ready to move to the next stage to access knowledge-in-waiting but lacks the maturity to achieve this. When the learner is assisted by a more experienced guide to develop knowledge-in-use they can reach the outer boundary of the ZPD. Wood et al (1976) built on this theory coining the term 'scaffolding' to explain the support given which is gradually reduced as the learner applies the knowledge and skills as they become independent learners. In other words, problem solving and learning is mediated (co-constructed) by the help of others. Learning was also promoted by the learner internalising the process through internal speech (Vygotsky & Luria 1930, Jordan et al 2008). Applying elements of Vygotsky's work to P-RNs

learning in the CLE, Spouse (1998) argued that scaffolding was provided by RM/Ms who identified P-RNs learning needs and articulated their own decision-making processes. In this way knowledge-in-waiting was applied to knowledge-in-practice (knowledge-in-use), which has the potential for reducing the theory-practice gap. Findings from my study also add support to Spouse's suggestions. Conversations between RM/Ms and P-RNs facilitated a co-construction of learning by recognising P-RNs' learning needs (knowledge-in-waiting) and translating the clinical situation and theory into language the P-RN could understand along with the application of theory (knowledge-in-use). For instance RM/Ms explained each step during last offices and CPR and answered P-RNs questions. Providing feedback and encouragement were important aspects of scaffolding P-RNs' learning; praising their communication with relatives and their performance of last offices inspired them to repeat that skill and validated these aspects of EOLC not explored in the HEI.

These learning conversations allowed RM/Ms to illuminate the tacit and often unspoken, aspects of decision-making in delivering exemplary nursing care. Tacit knowing/knowledge was originally described by Polanyi (1966) as knowledge that cannot be adequately verbalised since people are not always aware how their knowledge can be valuable to others. Dreyfus and Dreyfus (1980) proposed that tacit knowledge is an unconscious aggregation in the memory of experiences, episodes of activity and learning from others. Eraut (2004b) builds upon this arguing that tacit knowledge is a combination of formal and personal knowledge derived from experiences. Thus, people construct their view of the world via patterns stored as memories for comparison, called mental models, schemas (Bartlett 1932), personal constructs (Kelly 1955), schemes of experience (Schutz 1962) or maxims (Benner 1984, Herbig et al 2001). As discussed earlier, participants did not always have the range and variety of clinical experiences to create schema in EOLC, making it difficult for them to decide which knowledge was relevant to understand the situation and solve problems. Co-constructing knowledge in this way helped to develop P-RN's ability to think critically by using deep and surface approaches to learning (Marton & Saljo 1976a,b, Biggs & Tang 2007, Entwistle 2009, Bengtsson & Ohlsson 2010). P-RNs used their surface knowledge through assessing facts such as the normal range for patients' observation data, which then became a deeper approach as the RM/Ms packaged the information and procedures into



understandable schema to translate theory to practice and solve problems for patients and relatives. For instance, when a patient was deteriorating, whilst their observations were within the normal range, RM/Ms explained why there was a trend indicating signs of an impending cardiac arrest.

When support was omitted, learning was blocked and the P-RN continued to be a novice. In one example, a P-RN's first experience of last offices was undertaken without scaffolding support. Consequently, the P-RN left the room distressed and did not feel valued as a person. In contrast, her subsequent experiences were supported by a RM/M who encapsulated the principles of scaffolding. The RM/M discovered the P-RN's previous distressing experience before starting the procedure, explained each step and demonstrated dignity and respect towards the deceased. Afterwards support continued with feedback, an opportunity to ask questions and a plan for future experiences of last offices with other RM/Ms. This was important as the first experience of last offices without support could result in a P-RN remaining a novice. In contrast RM/Ms who scaffold learning assist the P-RN to evolve competence. A number of studies across the world have also described how RM/Ms share tacit knowledge with PRNs by discussing the reasons for decisions (Langridge & Hauck 1998, Donaldson & Carter 2005, Stockhausen 2006, Perry 2009, Keeling & Templeman 2013). Although these studies did not explore the potentially emotionally charged field of EOLC, the similarities suggest these may be components of a good RM/M in EOLC.

While scaffolding support is important other strategies also influence learning EOLC. Participants referred to conversations with exceptional RM/Ms as reflection or debrief. Reflection is a deep approach to learning as it promotes critical thinking (NMC 2010a). Reflection emerged from Dewey's (1933), Kolb's (1984) and Schon's (1983, 1987) concepts of learning from experiences. Schon (1987) argued that learning theory in a HEI is different to experiential learning as the real world is more complex. Reflection therefore provides an opportunity to apply theory to practice by identifying and critically challenging assumptions, exploring the influence of context on thoughts and behaviours and considering alternatives to transform the learner's understanding (Mezirow 1985, Brookfield 1987, Bulman & Schutz 2013).

Whilst Schon's (1983, 1987) ideas on reflective practice are widely accepted in the nursing profession, they are not empirically based and have been criticised for emphasising learners existing knowledge rather than focusing on generating new knowledge that expands learners knowledge in the workplace (Evans et al 2010). Some P-RNs in my study described critically reflecting with RM/Ms to identify their strengths and areas to develop in EOLC. It appears that P-RNs used the term reflection to encompass all learning conversations, which included scaffolding support to put the knowledge into the working environment. When the opportunities to undertake learning conversations were blocked, because they were not offered by the RM/M or, as in one case, refused, P-RNs learning stalled at being a novice.

This doctoral study reveals the importance of translating knowledge, scaffolding support and reflection through learning conversations and these have not been previously reported in studies of P-RNs' experiences of learning EOLC (see Chapters 2 and 3). So far this section has argued the co-construction of learning occurs through learning conversations. However, opportunities to translate knowledge were enhanced or inhibited by the sequencing of theory and practice and the context of learning in the CLE.

#### Sequencing of theory and practice and the theory-practice gap

Participants reported that prior to the first placement they did not feel ready to perform last offices, recognise signs of death, respond sensitively to distressed patients and relatives or manage their own emotions. Consequently P-RNs learning may stall at the novice stage, so that they appear to be a robotic nurse avoiding contact with relatives and patients. This thesis has important implications for nursing as it contributes to an understanding of how educational programmes can be sequenced to enhance P-RNs learning to manage the emotional impact of EOLC and enable them to deliver compassionate care and sensitive communication without appearing robotic or hardened.

Evans et al's (2010) four stage model describes the integration of knowledge into the workplace. The two steps related to the delivery of knowledge in the HEI, 'content re-contextualisation' and 'pedagogic re-contextualisation' will be compared and contrasted to my findings to explain the sequencing of EOLC theory and practice. Evans et al (2010) describe how practical workplace knowledge is changed and codified into a curriculum termed

'content re-contextualisation' (Evans et al 2010). EOLC is complex, delivered within the context of a caseload of patients. Patients have multiple morbidities and physical and psychological symptoms which interact, and patients and relatives may be distressed and uncertain of what is happening and so have challenging questions. Consequently delivering EOLC is multi-layered and can be challenging for the novice to learn. Traditionally knowledge has been decontextualized and codified into smaller simpler blocks, so the principles of symptom management and sensitive communication are easier to learn from a book or lecturers' presentations. However, a disadvantage of this simplification is that the complexity and sophistication of caring for patients is removed which may then make it difficult for the P-RNs to reapply in the CLE.

Evans et al (2010) term the sequencing and delivery of theory followed by workplace experience as 'pedagogic re-contextualisation'. My findings concur with Guille & Evans (2010) and Evans et al (2010) who argue that learning is enhanced by presenting the general principles in case studies from the workplace so that learners can re-conceptualise the principles they have learned. Participants in this study reported the lectures containing important factual theory of EOLC were useful for surface learning including the principles of the Gold Standard Framework (GSF 2012) and Advanced Care Planning (Marie Cure Cancer Care 2013). This literature is important as it informs team working between nurses and doctors to make decisions to meet patient's and relatives' needs. This lecture about EOLC was followed by PBL, which provided a framework on which to consider practice and new information. This enabled a deeper approach to learning and provided the opportunity to translate the theory of advanced care planning to patient care. In addition, there was co-constructed learning through sharing strategies to manage the emotional impact of EOLC to perform last offices and deliver sensitive communication away from the pressure of patient care in the CLE. This was appropriate in the second year of the programme as it allowed P-RNs to share their accrued expertise from the CLE.

However, my findings diverge from Guille & Evans's (2010) recommendation for the sequencing of theory before practice. Whereas, their study of aircraft engineers focused upon a specific technique or theory which was then explored in the workplace, nursing is multifactorial and complex, and involves vulnerable

people. Additionally difficulties in accommodating cohorts of 100 P-RNs to a hospice, elderly care and cancer units to experience EOLC immediately following theory is an unobtainable goal and perennial challenge. Even if P-RNs are fortunate to have this recommended sequencing of theory and clinical experience there is no guarantee a patient will die during the relative brevity of their placements. On the other hand, P-RNs reported being expected to care for dying people in the first year of the programme.

It has been argued that curriculum design has traditionally focused upon delivering technical knowledge and skills that are vital before the first placement (Upton 1999). Although, there was a session about grief and loss in the first year many of the participants did not remember this and requested more teaching about the effects of death, last offices and strategies to manage the emotional impact. Therefore, it is argued that the perceived lack of preparation for the first death created a gap between theory and practice. This gap does not align with the traditional definitions of a translational theory-practice gap in which the HEI teaches the ideal rather than the reality of nursing, nor a relevance theory-practice gap when theory is not considered applicable so not adopted by RNs in the CLE (Upton 1999, Risjord 2011). There seems instead to be a mismatch in the timing of theory and practice that inhibited opportunities for RM/Ms to translate theory into practice. This builds upon Allan et al's (2008) theory of the uncoupling between theory and practice, in which P-RNs found their supernumerary status a hurdle requiring learning opportunities to be negotiated with their mentors. In my study, the lack of EOLC theory before the first placement made it more difficult for P-RNs without previous experiences of EOLC to know which knowledge to seek out and what strategies were available for managing the emotional impact of seeing a dead person, distressed patients and relatives. The exceptional RM/M recognised this gap and by translating the theory into practice, co-constructed learning with the P-RN to enable the development of competence. However, P-RNs paired with a robotic RM/M did not experience this translation, the gap was not recognised or addressed and without understanding the underpinning rationale or theoretical knowledge, their ability to adapt the knowledge to each situation was limited.

In the literature there is little empirical evidence comparing the sequencing of theory and practice. Research into learning the theory of EOLC reviewed in

Chapter 2, explored changes in knowledge, attitude and behaviour but did not compare the sequencing of theory and practice. Falk et al (2016) compared two groups of second year P-RNs in Sweden who either received theory then attended placement (n=60), or a placement followed by theory (n=60). Although both groups reported that theory should precede practice, it concluded that the sequencing of theory was subordinate to a mentor who enhanced P-RNs deep approach to learning through reflection and problem solving. This concurs with my findings that the RM/M who was able to recognise the P-RNs gap in knowledge and then translate theory into compassionate patient care, appeared to reduce the theory-practice gap.

#### Aspects of the clinical learning environment and the theory-practice gap

Participants reported that opportunities for learning conversations were influenced by social-contextual factors in the CLE including caseload and inter-professional decision-making and consequently their learning may have either stalled or progressed. These findings concur with Allan et al's (2008, 2011) study of RNs, lecturers and P-RNs, which reported P-RNs learning conflicted with the increasing demands of patient care and consequently inhibited RNs ability to facilitate learning thereby exacerbating an 'uncoupling of theory and clinical learning' (p4). This can be explained partly by the increased volume of acute care in hospitals and the priority of ensuring patient safety, which can be compromised by lower nurse to patient ratios (Ball & Pike 2009, RCN 2010, Hospital Episode Statistics 2015). O'Driscoll et al's (2010) survey of 814 P-RNs in England reported workload interfered with learning and was statistically significantly associated with student likelihood of experiencing stress and anxiety. In contrast, it can be argued that the one nurse to one patient ratio in ITU provides better opportunities for high standards of EOLC (RCN 2010). Participants reported more opportunities for learning conversations and working alongside RNs in A&E, ITU and hospice settings which may have been influenced by the nurse:patient ratio.

Learning sensitive communication appeared to be encouraged in areas prepared for end-of-life conversations. ITU, A&E, cystic fibrosis unit and a hospice all included rooms dedicated to conversations with relatives. Although some wards did not have dedicated rooms, sensitive communication was also reported in elderly care. This may be explained by death occurring relatively

frequently and learning to deliver sensitive communication between nurses, patients and relatives was underpinned by guidelines for EOLC in Cystic Fibrosis, (Cystic Fibrosis Trust 2011), ITU (Faculty of Intensive Care Medicine/The Intensive Care Society 2013) and A&E (Royal College of Emergency Medicine 2012, 2015) and was embedded within the culture encouraged by ward managers.

Participants also reported that learning was enhanced in clinical environments that promoted inter-professional decision-making through multidisciplinary meetings or debrief as reported in examples from A&E, ITU, hospice and the cystic fibrosis unit. Lawton (2000), discussing interdisciplinary working in ITU and A&E, suggests that RNs in these areas have developed the technical knowledge of advanced assessment, nurse prescribing and advanced life support which the doctor's perceive as more valuable than nurses' roles that focus on personal hygiene for example, personal hygiene. However, a more compelling explanation may be that working relationships in ITU, A&E and care environments for long term conditions allows for prolonged interaction, leading to mutual respect for each other's knowledge and skills. Subsequently, these interactions are embedded in EOLC guidelines and endorsed by managers in hospices, Cystic Fibrosis Unit, (Cystic Fibrosis Trust 2011), ITU (Faculty of Intensive Care Medicine/The Intensive Care Society 2013) and A&E (Royal College of Emergency Medicine 2012, 2015). Consequently, these environments provided the opportunity for P-RNs to witness inter-professional decision-making to understand the rationale for choices in care and therefore enhanced their learning EOLC and competence. In contrast, learning was inhibited when these opportunities for knowledge development were not made available.

### **Learning through role modelling**

Modelling RM/Ms' responses to patients and relatives was considered a key component of learning interpersonal skills. Participants made a distinction between the exceptional RM/Ms that they wished to emulate and robotic RM/Ms whose behaviour they rejected. Participants drew on these behaviours to develop personal values to guide EOLC that appear to align with the behaviour of the exceptional RM/M who facilitated their learning. However, it is concerning that if only robotic RM/Ms were available then P-RNs may

incorporate avoidance behaviours into their personal values of EOLC. Without exceptional RM/Ms, some participants learned through trial and error and were uncertain if they had responded effectively to support the patient, resulting in confusion and distress.

Although role modelling theory did not emerge from nursing it is recognised as a powerful form of learning between RNs and P-RNs (NMC 2010a). Bandura and Walters (1969) theory of social learning explains role modelling through observing other people. Bandura (1986, 1997a), developed this into social cognitive learning as a two way interaction between an individual and his/her environment so that observing behaviour allows complex patterns and language to be acquired in a more efficient way than through trial and error. Bandura (1997a) argues that learning extends beyond observing and involves four processes: attention, retention, motor reproduction and motivational processes.

Some participants' findings were similar to this framework. They described observing RM/Ms who demonstrated sensitive communication (attention). These findings concur with Bandura's argument that behaviour is more likely to be imitated (motor reproduction) when there is an opportunity to promote retention and self-efficacy. Participants reported rehearsing components of CPR, last offices and sensitive communication by discussing the steps in the procedures with RM/Ms (retention). These discussions helped P-RNs to move towards a deep approach to learning by translating theory into understandable schemas. Participants reported feeling encouraged to adopt and repeat the skills of performing last offices, CPR and sensitive communication when mentors gave them positive feedback and praise (verbal persuasion). This motivation is explained by Bandura (1997b) as a belief in their ability to complete the task known as self-efficacy. The findings in this investigation concur that self-efficacy can be influenced through the success or failure of a previous task (enactive mastery) (Bandura 1997b). In addition P-RNs reported improving their performance when they observed role models who described how they had similar fears but gradually reached a mastery performance (vicarious experiences) (Bandura 1986, 1997b). In contrast when feedback was not supplied participants relied upon self-reinforcement through feelings of

personal achievement; however learning stalled due to uncertainty whether their selected strategy to respond to relatives or patients, was effective.

However, P-RNs adopted some behaviour but not all. Bandura argued the behaviour was more likely to be copied if 'modelled behaviour has an outcome they value' (Bandura 1997b p29). Participants differentiated between exceptional RM/Ms they wished to emulate and hardened/robotic nurses who provided physical care to patients but did not explore psychological support through sensitive communication, thus appearing mechanistic and without compassion. Indeed a translational theory-practice gap was identified when participants discussed how recommended evidence based communication techniques taught in the HEI were not always demonstrated by RM/M (Risjord 2011). One explanation for this is consistent evidence that some RNs have not acquired the knowledge and skills in compassionate EOLC and sensitive communication as P-RNs (Bergen 1992, Hopkinson et al 2003, NAO 2008, DH 2013, NCPIC 2016). Another possible reason is a culture that promotes RNs avoiding talking with patients and relatives in order to protect themselves from the emotional impact (Menziez 1960, Benner & Wrubel 1989, Fabricius 1991a,b, 1995, 1999, Fulton 2008, Pereira et al's 2011). This behaviour may also develop when an RN experiences emotional exhaustion and burnout so that the nurse feels unable to give any more of their emotional self and so starts to protect themselves (Pereira et al 2011).

Participants worried that if they observed insensitive communication or nurses avoiding patients and relatives they would become robotic themselves. These concerns suggest that positive and negative role models influence P-RNs' development of their personal and professional values in EOLC. Therefore, this thesis argues that modelling exceptional RM/Ms is a core component of evolving competence to provide compassionate sensitive EOLC. Moreover a main component in evolving competence is P-RNs' ability to discern between exceptional RM/Ms and hardened/robotic RM/Ms in order to decide which behaviour to model in their professional values and behaviour.

Bandura (1986) suggests that the more numerous the contacts with a role model the more likely the behaviour will be incorporated into the learners behaviour. This thesis builds upon this as participants often reported learning from single encounters with doctors, CNS and ward nurses. These encounters



were powerful and memorable as they revealed sensitive communication they wished to emulate. Bandura (1997b) also postulated that 'individuals are more likely to adopt a modelled behaviour if the model is similar to the observer and is admired' (p30). Some RM/Ms held in high esteem were described as experienced CNSs and others as young and newly qualified. The literature explains that newly registered nurses may be more supportive as they remember their experiences as a P-RN (Langridge & Hauck 1998, Donaldson & Carter 2005, Perry 2009).

A compelling finding was that many participants were afraid they too would become robotic nurses. This has important implications for developing compassion as when P-RNs do not have the opportunity to observe an exceptional RM/M and do not recognise poor communication they may unwittingly adopt the behaviour of robotic RM/Ms. As a result a P-RN may remain a novice, rather than moving towards evolving competence but be unaware of this. Participants also suggested that P-RNs may leave nursing if they are unable to manage the emotional impact of undertaking EOLC communication. The challenge for the nursing profession is to explore how to retain positive personal values so that nurses do not become robotic. One method revealed in this thesis is ensuring P-RNs work with exceptional RM/Ms. Role modelling was an important component of learning that was also influenced by the P-RNs motivation to learn which is explored in the following section.

### **Motivation to learn end-of-life-care**

The nursing profession aims to create life-long learners who recognise gaps in their knowledge and skills and rectify this through self-directed learning/self-regulated learning (SDL/SRL) (NMC 2010a, DH 2012b). A weakness of the studies in education and experiences in EOLC reviewed in Chapters 2 and 3 is that they omitted to explore SDL/SRL strategies. This raises the question of how P-RNs identify what they need to know to provide EOLC. My thesis addresses this lack of research by contributing an understanding of the SDL/SRL strategies used by P-RNs to enhance learning EOLC.

Participants' previous professional experiences as an HCA and/or personal experiences as a relative contributed to their motivation and awareness of the

skills and knowledge they needed to develop. In contrast, others with little previous experience reported their desire to learn emerged as they were exposed to experiences with patients, relatives and RM/Ms during the programme. Participants' motivation to evolve competence concurs with Knowles' (1990) humanistic theory of andragogy and self-directed learning (SDL). Knowles (1990) argues that people are motivated to learn what they perceive they 'need to know' and demonstrate a 'readiness to learn' when they are aware of why a topic is important and useful 'to grow and develop' (p172). This is similar to P-RNs motivation which arises from positive previous experiences as a relative when a RNs sensitive communication inspired them to learn. Conversely, negative experiences such as the perceived lack of compassionate care of a relative, stimulated P-RNs to provide care with dignity and respect. Furthermore, it is possible that EOLC education delivered in the HEI provide suggestions of areas to develop with mentors in the CLE. Participants demonstrated a readiness to learn to provide compassionate EOLC which instigated setting personal learning goals. However, SDL theory explores only the readiness to learn, not the strategies for achieving and evaluating the goals (Mezirow 1985).

Research has explored the strategies used that stimulate learners to take responsibility for their learning through Zimmermann and Schunk's (1989, 2011), theory of self-regulated learning (SRL). Underpinned by theories of cognitive psychology and empirical evidence, SRL investigated the thinking processes of learning (metacognition) used by children to solve mathematical problems. There are four steps in SRL underpinned by the belief that one can succeed (self-efficacy) and influenced by the tasks' level of difficulty and time available (Zimmermann & Schunk 2011). These steps will be compared to the findings to understand the strategies used to learn EOLC. The first step is forethought and planning by identifying goals (Zimmermann and Schunk 1989, 2011). As participants experienced a variety of placements, EOLC and RM/Ms, they responded by creating goals and objectives to learn to deliver EOLC. The second step is performance, whereby P-RNs employed strategies to compare their own performance to a standard. In one example, participants compared their communications skills to those of a RM/M they considered to be exceptional in delivering sensitive communication. The third step is self-reflection through making judgements and inferring causal attributions to make

changes to enhance future sensitive communication. The final step is control of the social and physical setting by seeking help from peers and nurses to learn to deliver sensitive communication.

This was important as participants who had developed the skills of SDL/SRL were able to compare their personal values, to reveal a gap in knowledge and skills and responded to robotic RM/M by seeking out exceptional RM/Ms to evolve competence in EOLC. In addition, participants developed confidence as they accrued clinical experiences of EOLC (self-efficacy). They reported that this behaviour was encouraged by mentors who also sought out learning experiences for them and provided verbal persuasion through praise.

However, there are several limitations to SRL as a theory to explain learning EOLC in this investigation. Firstly, SRL emerged from observing children learning to apply mathematical formula in school. In contrast learning EOLC is more complex as RM/Ms may model either sensitive communication or robotic behaviour. Therefore, participants needed to be discerning and choose which behaviour to incorporate into their personal values. Participants were concerned that without examples of exceptional RM/Ms, some P-RNs may not be able to discern between sensitive communication and robotic RM/Ms, indeed there were examples of RM/Ms modelling avoiding communicating with distressed patients and relatives.

In addition, it is unclear how P-RNs developed their own SRL strategies. Paris and Paris (2001) propose SRL is facilitated by a lecturer as it does not develop automatically either as people get older or from a learning environment. There is some evidence that P-RNs develop SRL as they progress through their training (Mullen 2006, Kuiper et al 2010, Dunn 2012). SDL has been promoted through e-learning, preparatory reading, enquiry based learning and problem based learning (Levett-Jones 2005, Smedley 2007, Sharples & Moseley 2011, Petty 2013). However, none of these studies explored EOLC. Evans et al (2004) reported that people learning about social care drew on tacit knowledge and skills from their personal life experiences such as caring for family, and that this helped to motivate them to learn and develop strategies to succeed. Similarly participants in my thesis drew on their previous personal experiences of EOLC to motivate learning compassionate care, create personal objectives and deploy knowledge.

In contrast, P-RNs without prior experience in EOLC may have insufficient knowledge to instigate SRL. As participants experienced a variety of placements and RM/Ms, they responded by creating goals and objectives, motivated to build upon their learning in each placement. P-RNs may have wanted to develop more knowledge and skills following an experience where they did not know how to respond to distressed relatives/patients or felt uncomfortable. In addition they were motivated to repeat performing last offices and CPR to refine their skills. Returning to Evans et al's (2004) concept of 'learner re-contextualisation,' participants SDL/SRL strategies identified above appeared to be important factors towards their motivation and ability to process their learning alongside RM/Ms to shape personal values of compassionate EOLC. These values developed as participants shared their experiences and supported each other to manage the emotional impact. Therefore this thesis argues that building SRL strategies as P-RNs may assist the continued development of EOLC on registration. However, if the knowledge and skills are not developed they may remain a novice unsure how to respond to patients and relatives in new situations. In addition, as EOLC can be emotionally distressing, this will be now be explored in relation to P-RNs learning.

### **Learning to manage the emotional labour of end-of-life-care**

The NMC (2008a, 2010a) requires nurses to demonstrate competence in sensitive communication and providing care with dignity and respect, both of which are integral to EOLC. However, participants reported that the emotional impact of witnessing distressed patients and relatives, observing the process of dying and seeing a dead person may influence EOLC. These results are consistent with studies reviewed in Chapter 3, although these failed to give sufficient consideration as to how P-RNs learn to manage the emotional impact. My thesis is important as it explores this gap in the evidence by developing an understanding of the factors that contribute to P-RNs emotional distress and how this may impact on learning.

It is argued that nurses use their emotional intelligence to recognise the emotional impact upon patients and empathise with them, which influences the care they deliver (Goleman 2001, Freshwater & Stickley 2004, McQueen 2004). Participants reported how they expected to be emotionally engaged with patients and relatives to communicate sensitively and did not want to appear

hard like the robotic RM/Ms. These challenging conversations about pain, sadness, diagnosis and prognosis reveal the emotional demands of working with patients and relatives is as hard as physical and technical labour, so this is termed 'emotional labour' (Smith 1992, 2012). Indeed Theodosius (2008) argues that therapeutic emotional labour creates the identity of a nurse. Therefore, the ability of P-RNs to manage the emotional impact while interacting with patients and relatives is considered a prerequisite for EOLC.

The emotional impact of EOLC and last offices can be moderated by a number of factors. Lawton (2000) argues that whilst palliative care nurses see a lot of death, they are more likely to have established a relationship with the patient and family and therefore an emotional bond and strategies to manage this impact. However, empathising creates a bond so that P-RNs may be vulnerable to an emotional impact (Lawler 1991). Many participants in this thesis described being initially overwhelmed by emotions so that they found it difficult to talk with patients and relatives. Alongside this P-RNs may not have prior experience of the smells of illness such as diarrhoea, vomit and disintegration of tissues due to an increase in life expectancy, reduction in child mortality and the movement away from caring for relatives at home (Lawler 1991, Lawton 2000). Lawler (1991) and Lawton (2000) described the care of the 'unbounded body' for a person, with for example incontinence or a fungating wound, as dirty work, since nurses are in direct contact with body fluids and odours. These studies explored RNs experiences in hospices (Lawton 2000) and hospitals (Lawler 1991). However, neither explored how P-RNs learn strategies to manage these within the competing demands of a busy hospital ward. My study is important as P-RNs witness illness or death and these findings contribute towards an understanding of how HEIs and RM/Ms can assist the development of strategies to manage the emotional impact of the unbounded body in the hospital environment.

In addition, there is evidence that for some P-RNs with personal experiences of grief, providing EOLC and conversing with patients and relatives may awaken personal loss and pain that may inhibit their ability to provide EOLC (Kiger 1994, Allchin 2006, Terry & Carroll 2008, Parry 2011). This effect is explained by Stroebe and Schut's (1999) 'Dual Process Model of Coping with Bereavement,' which suggests that people facing loss, oscillate between loss-

orientated stressors of grief, denial and avoidance and restoration-orientated stressors that adapt to the loss. Particular memories may trigger pain and intense emotions moving a person to loss orientation. In my investigation, participants' personal experiences were a potential source of loss and pain that motivated learning to provide compassionate EOLC. However, those that may be experiencing personal grief may not have volunteered for this study.

Finally, an alternative explanation of P-RNs descriptions of 'shaking' and 'crying' following CPR could be explained as a stress response caused by the release of adrenaline and noradrenaline which enhanced the management of the situation. Then as the stress reduces, adrenaline falls and a physical rebound response such as crying and shaking occurs (Charney 2004). Having explored the causes of the emotional impact the influence upon learning is now examined.

#### The effect of emotional upset upon the learning process

The findings from this study show that participants were often emotionally upset when learning EOLC, but it was unclear how this influenced their ability to learn. A few studies have explored the effect of emotion upon learning. Physiologically Damasio's (1996) study revealed the stress response causes hypothalamic-pituitary-adrenal-axis to increase cortisol which raises the heart rate and interactive involvement with cognitive functions of memory structures which have an active role in processing emotional information (Damasio 1996). It is difficult, therefore, to disengage attention from the emotional qualities of a stimulus, particularly negative stimuli such as fear or anxiety (LeBlanc 2012). LeBlanc (2012) reported the effect of stress upon 22 paramedics. Those in a high stress situation had increased cortisol, raised anxiety scores and difficulty recalling information for drug calculations. Although not conducted among P-RNs this work highlights the effect of stress on memory recall and this might explain why learning is inhibited when people are anxious.

Few studies have explored the effect of emotions upon nurses' learning. In the USA, Bell (1991) measured anxiety levels by comparing learning to perform a female catheterisation by either watching a video versus being taught in a skills laboratory. Anxiety was less for the taught group suggesting that interaction to ask questions and practice skills reduces anxiety and promotes learning (Bell 1991). Cheung & Au (2011) tested the causal relationship between anxiety

levels and clinical performance in two groups of third and fourth year undergraduate nurses in Hong Kong. Both groups watched a video about removing sutures, followed by either an anxiety mood induction (video about occupational health risks of severe acute respiratory syndrome) or a calm mood induction video. The study reported students were statistically significantly less proficient in performing the skill after an anxious mood induction, suggesting anxiety impairs clinical performance. Suliman & Halabi's (2007) study of 105 first year and 60 fourth year baccalaureate P-RNs in Saudi Arabia reported that critical thinking was positively correlated with self-esteem and negatively correlated with state anxiety. Furthermore, self-esteem correlated negatively with state anxiety. This suggests P-RNs may find it more difficult to undertake a deeper approach to learning when anxious. Whilst the evidence is limited and from different parts of the world it appears that anxiety may influence P-RNs cognitive learning.

Pekrun (1992) and Pekrun et al (2007) developed a conceptual model of the effects of emotion on learning and achievement in children and adults. They theorised that some stress and anxiety enhances memory storage and promotes achievement but an overload of stress or anxiety may hinder the storage and retrieval of knowledge and subsequently learning. Pekrun (2007) determined that the cognitive component of emotions such as fear, sadness, worry and anxiety tend to occupy a person's mind, creating an attention deficit that impedes learning. In contrast, extrinsic motivation such as knowledge perceived as relevant and interesting may produce positive emotions of interest, hope and enjoyment and enhance learning. In my study although participants were emotionally distressed their motivation to provide optimal EOLC appeared to enhance their desire to learn.

Clouder's (2003) study among occupational therapists and physiotherapists described learning when knowledge is 'troublesome.' This involves a messiness in which practice may conflict with the individual's personal ideals of optimal care. Yet Meyer & Land (2003) argue learning still occurs when the individual draws on emotional capital in situations of indeterminacy. Therefore emotions create a rich context that promotes learning. Although Clouder's (2003) study did not include P-RNs there are similarities between these caring roles that may explain why learning may occur despite the emotional impact, due to the desire

to improve a patient's situation. Participants in my study drew upon personal experiences of caring for relatives to develop personal beliefs into what constitutes compassionate EOLC. This contrasts with findings from studies by Kiger (1994), Allchin (2006), Terry & Carroll (2008) and Parry (2011), which described flashbacks to the deaths of family members as causing emotional distress that resulted in P-RNs avoiding patients and relatives. However, these studies investigated first and second year P-RNs, who may not have developed enough strategies compared to final year students.

#### Developing strategies to manage the emotional impact of providing EOLC

Having explored the potential causes of emotional impact and the effect on learning, the strategies participants used to enable participants to provide compassionate EOLC and sensitive communication are now examined.

Participants normalised some deaths by explaining that it was a release from pain, dementia or physical deterioration. This developed from their increased knowledge and understanding about diseases and symptom management from lectures in HEI, reading and experiences. As they progressed through the programme, participants developed self-efficacy as they saw their patients becoming more comfortable due to the care they delivered and also received positive comments from relatives and RM/Ms. This in turn contributed to cathartic, rewarding experiences that may have moderated the emotional impact. These were similar strategies to manage the emotional impact identified by RNs in a hospice (Ablett & Jones' (2007). However, Ablett & Jones (2007) did not report how these strategies were learned.

Psychoanalysts, Menzies (1960), Fabricius (1991a,b, 1995) and Speck (2003) recommend that an important aspect of nurses managing their grief is the acknowledgment that their emotions are a normal response. This was a common strategy among P-RNs in other studies (Kiger 1994, Cooper & Barnett 2005, Parry 2011). Importantly participants in this doctoral study also expressed the need to release their emotions with friends. It could be argued that these important discussions among peers revealed P-RNs emotional intelligence through their empathy for each other, patients and relatives. As a result this facilitated an understanding of how to manage their emotions that may be translated into being compassionate to peers, patients and relatives. In addition, writing the story also allowed a participant to release their emotions to



put them to one side to facilitate the healing process (Gersie1991, Wakefield 2000).

Participants were selective and did not talk with non-nursing relatives and friends as they believed they would not understand their experiences. This contrasts with studies by Kiger (1994), Loftus (1998), and Parry (2011) who reported how P-RNs found talking with their family was supportive. However, these studies fail to identify whether family members had a healthcare background which would help them understand the impact of EOLC. Instead of talking with family and friends some participants learned to demarcate between work/professional and home/personal lives through personal reflection on what they had done well and what they would change to enable them to release their emotions before they got home. This concurs with Spouse (2003) and Smith's (2012) studies of P-RNs in the UK which also revealed demarcating between home and work was an important strategy that enabled P-RNs to be able to interact and relax with families and friends to manage the emotional impact.

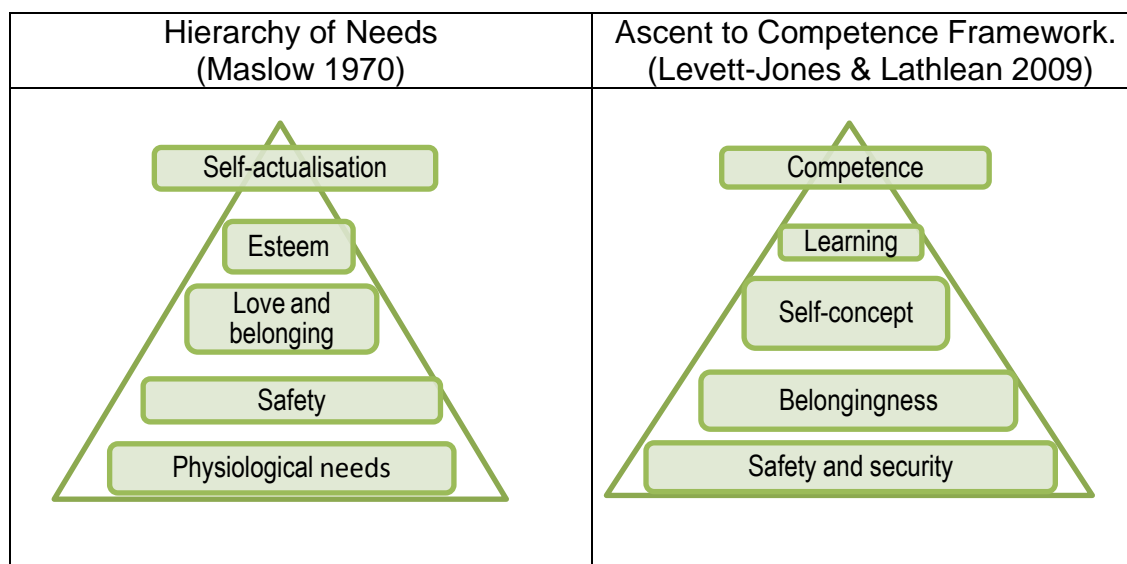
Contrary to similar studies in the UK (Kiger 1994, Terry & Carroll 2008) participants did not mention personal tutors or link lecturers as sources of learning or emotional support. This was unexpected as the RCN (2006) and NMC (2010b) recommend nurse lecturers support mentors and P-RNs in the CLE and in the HEI. Reasons for this are unclear, however it is possible link lecturers/personal tutors feel less connected to the CLE as they are located in HEIs (Allan et al 2008, 2011). Alternatively it has been argued that the lack of a universal culture of reflection on emotion management among nurses can mean lecturers do not always have the skills to facilitate such discussions (Fabricius 1991a,b). Where support, has been offered to P-RNs to promote learning strategies to manage the emotional impact of nursing, participation varied as the more emotionally mature completed the programme. However, it is unclear if those who did not attend gained skills to manage emotions to enable delivering compassionate care (Fabricius 1991a,b). This echoes findings from PRN's in my study who sought out and received emotional support from RM/M and other P-RNs and subsequently reported they felt more able to provide EOLC. However, it is unclear where those who did not seek out support gained strategies to manage their emotion to provide compassionate care or without those skills avoided conversations with the distressed. As the majority

of learning was alongside RM/Ms it necessary to explore how an emotionally safe learning environment can be created.

### Promoting a safe learning environment

As discussed above it is evident that RM/Ms are central influences that enhance or inhibit the translation of knowledge in EOLC. However, participants were uncertain of their skills in performing EOLC which caused an emotional impact. Learning appeared to be enhanced when P-RNs felt they were supported emotionally in an environment free from threat by a lecturer or RM/M, who was genuine, could be trusted and was empathetic to their experiences. This is a key component of the theory of andragogy (Knowles 1990), Tennant's (2006) reconstructed andragogy and Rodgers (1969) freedom to learn. However, none of these are based upon empirical evidence into how emotions can affect P-RNs learning. P-RNs learning in clinical environments has been explored by Levett-Jones and Lathlean (2009). This research led them to develop the 'Ascent to Competence' adapted from Maslow's (1970) theory of Hierarchy of Needs for Motivation (Figure 6.2).

Figure 6.2 Comparisons of Maslow's Hierarchy of Needs and the Ascent to Competence Framework (adapted from Levett-Jones & Lathlean 2009)



In Maslow's (1970) framework the pinnacle 'self-actualisation' is achieved through creativity, spontaneity and problem solving to achieve the best possible for that individual. The pinnacle in 'Ascent to Competence' is achieving 'competence' to provide patient-centred care (Levett-Jones & Lathlean 2009).

Conversely, when P-RNs did not feel welcomed or acknowledged but alienated, anxious or afraid without support they did not feel safe and were less motivated to learn.

Levett-Jones and Lathlean's (2009) study did not explore EOLC nevertheless, there are some similarities. The findings in my thesis also described P-RNs learning being enhanced when they experienced emotional and psychological 'safety and security.' It was encouraging in my study that there were many reports of RM/Ms who recognised and valued P-RNs emotional response as normal and gave the individual the option for time away from the situation. Importantly participants were not abandoned, but learned to manage emotions when RM/Ms translated the event alongside sharing strategies for emotional management while remaining compassionate. These conversations created a feeling of being part of the healthcare team akin to Levett-Jones & Lathlean's (2009) description of 'belongingness.' In addition participants reported feeling valued when praised for their sensitive communication and EOLC and when performing CPR appeared to create what Levett-Jones & Lathlean (2009) termed a 'self-concept,' of being able to work more independently with more responsibility. These factors contributed to a readiness for 'learning' when RM/Ms translated knowledge into patient care and consequently assisted P-RNs to evolve competence as they became self-directed learners.

In my study learning was inhibited by a RM/M who did not recognise the emotional impact on the P-RN of seeing the deceased and distressed patients and relatives. In addition, learning was inhibited when the RM/M did not explain the procedures or provide an opportunity to reflect upon how P-RN's could learn to manage their emotions while being compassionate. This concurs with McGarth & Higgin's (2006) study of P-RNs which also argued that failure to reflect/debrief following an emotionally upsetting event may leave the learner feeling unsupported and inhibit their learning. A potential consequence of the emotional impact not being explored is that P-RNs may not feel safe and so may protect themselves through avoiding distressed patients and relatives. As a result they remain a novice unaware that they are perpetuating the development of robotic nurses and not developing competence in EOLC.

Levett-Jones and Lathlean (2009) also reported P-RNs who did not feel they belonged in the CLE were less likely to undertake SDL/SRL. This thesis builds

on this as some participants reported SDL/SRL when they did not feel valued as they sought out exceptional RM/M or nursing friends who could supply emotional support, knowledge or skills. However, those who did not instigate such learning may not have developed knowledge and skills and remained a novice. Finally this thesis also revealed that when learning in smaller groups with lecturers that facilitated their understanding of EOLC, last offices and sensitive communication participants also felt valued as individuals and appeared to become more ready to learn. Therefore, creating a supportive environment underpins every aspect of learning EOLC (Figure 6.1).

### **Summary**

This study argues that EOLC is an intrinsic part of nursing and providing high quality knowledgeable care is important as when this is delivered in an uninformed and unsupportive way it may result in distressed patients and relatives. However, P-RNs do not know how to deliver compassionate EOLC unless they learn the theory in HEI and are exposed to experiences in the CLE. Due to the differing contexts of learning, knowledge is not a straight transfer from lectures to patient care or between different patients. Therefore, it is not enough to only observe care, in addition further learning is required by the RM/Ms translating this knowledge into understandable language and EOLC. This is concordant with both social cognitive theory views of learning, which emphasise acquiring knowledge through the co-construction of learning with an expert and social learning by role modelling another's behaviour. The creation of a safe learning environment that recognised the learner as an individual formed a foundation which promoted a readiness to learn. These behaviours nurtured P-RNs motivation to self-direct/regulate their learning. As a consequence, translation of knowledge and skills contributed to evolve into competence in EOLC.

### **Limitations and strengths of this study**

As with any research, findings are constrained by a number of limitations. An inherent limitation in this study was that this was completed in one Faculty of Nursing and Midwifery situated in an HEI. Nevertheless participants experienced EOLC in placements located in four NHS Trusts which gave a broader perspective. The focus group discussions revealed an in-depth

exploration of the education delivery in this organisation and identified areas to develop to enhance learning EOLC.

A further limitation is the sample may have an element of bias since P-RNs who experience flashback/resonance with family members may not have participated. Alternatively some participants may not have wanted to share their personal experiences within the group. The sample was relatively small at 12 participants and P-RNs are not a homogenous group, therefore caution must be applied as the qualitative findings may not be transferable to the wider population. The gender imbalance also limited the findings as one male P-RN participated and additional men might have given a different perspective. Nevertheless, these participants revealed rich data that gave an insight into the complexity of P-RNs learning EOLC.

Data were collected from two focus group discussions and a paired interview, which had some inherent limitations. It was difficult to know if participants agreed about a topic when the group contributed 'yes.' Also, some participants may not have revealed all their opinions. These were addressed during the data collection as the moderator encouraged the discussion to progress. When each participant's contribution was transcribed each had contributed ten pages of text, which suggests that all participants were able to contribute.

A final limitation is the focus group discussion is reliant upon self-report and memory (Morgan 1997). Although we will never know what might have been revealed in the privacy of an interview or during participant observation, these participants elaborated upon each other's opinions. At the very least this provided the opportunity to reflect upon factors that inhibited and enhanced learning EOLC that provided very rich data. Having discussed the findings and limitations of this investigation, the following chapter will summarise the key findings then explore recommendations for education, clinical practice and research.

## Chapter 7 Conclusion and recommendations

### Overview of findings

This thesis explored undergraduate pre-registration nurses' perceptions of how learning end-of-life-care could be enhanced in the Higher Education Institute (HEI) and Clinical Learning Environments (CLE). The exploration comprised a review of the published evidence into EOLC education, a meta-ethnography synthesising P-RNs experiences of providing EOLC and an empirical study involving focus groups which provided insights into P-RNs learning not previously explored.

While the meta-ethnography revealed that care-of-the-dying may have an emotional impact on P-RNs, the studies did not reveal P-RNs and RNs characteristics that enhanced their learning of EOLC. Importantly this investigation offers insight into factors not previously explored that enhanced P-RNs learning to manage expected and unexpected death, communicate sensitively with patients and their relatives and perform last offices before they qualify. Learning EOLC was a process in which P-RNs moved between being a novice and evolving competence and personal values in EOLC. The transition to competence was enhanced by the translation of knowledge between the HEI, RM/M and P-RN. These properties do not occur in isolation but are interconnected like cogs in a machine. When these interconnections enhanced learning, the P-RN moved to evolving competence and personal values in EOLC. The six key findings from this study are:

1. Participants learned the theory of EOLC in the HEI, whilst most learning occurred alongside RM/Ms in the CLE. The HEI played an important role in supplying the building blocks to learning the theory of EOLC. This was coupled with a deeper approach that translated theory during PBL and opportunities to practice communication skills. Learning was enhanced when P-RNs felt able to share their experiences of EOLC and last offices with each other.
2. Many participants provided EOLC during the first year but were taught the theory during the second year. Thus participants felt unprepared for recognising the physical signs of death and for responding to distressed patients and relatives. This suggests an uncoupling of theory and

practice. In addition the skills of sensitive communication explored in the HEI, were not always observed among RM/Ms in the CLE. This suggests there is a tension between theory learned in HEI and observed practice, which may indicate a translational theory-practice gap (Risjord 2011).

3. Learning was enhanced when RM/Ms translated theoretical, tacit and experiential knowledge into language P-RNs could understand enabling both surface and deeper approaches to learning. This was enhanced by RM/Ms:
  - a. creating an emotionally safe learning environment by acknowledging the emotional impact of EOLC and sharing strategies to help P-RNs manage their emotions
  - b. scaffolding support through learning conversations that identified gaps in knowledge and shared theoretical and experiential knowledge to assist P-RNs develop their own schema for delivering compassionate EOLC
  - c. explaining procedures and their decision-making processes
  - d. modelling sensitive compassionate care and communication
  - e. guiding P-RNs reflection to explore strengths and how to respond to similar situations in the future
  - f. enhancing P-RNs self-efficacy through positive feedback
4. Learning was enhanced when the CLE promoted P-RNs attendance at multi-disciplinary team meetings to witness inter-professional decision-making after cardiac arrests in A&E, at the bedside in ITU and through weekly meetings in cystic fibrosis units and hospices. This allowed P-RNs to develop a greater understanding of the decisions made which they could apply to future care.
5. Learning was inhibited when RM/Ms did not use many of the components that enhance learning EOLC. This lack of opportunity to translate theory into compassionate EOLC appeared to cause P-RNs learning to stall or regress to being a novice in EOLC.
6. P-RNs were ready and motivated to learn. They drew upon their personal and professional knowledge of EOLC gained both before and during the programme. P-RNs self-regulated their learning by creating learning objectives, seeking out learning opportunities and developing strategies to manage their emotions in order to deliver sensitive care by reflecting with nursing friends. Importantly P-RNs were active learners

who drew together theoretical and experiential knowledge to develop personal values that guided them during EOLC. The challenge for RNs is how to retain these values so that they are not eroded with the risk of becoming robotic.

### **Recommendations for nursing education**

It is recommended that the knowledge and skills to provide EOLC are taught in incremental steps throughout the three years of the programme. A consistent suggestion for improvement was having a small group session prior to the first placement. This could offer an explanation of what happens physiologically when a patient dies following recommendations on performing last offices by the National End-of-Life-Care Programme and National Nurse Consultant Group (Palliative Care) (NHS 2011). In addition this would be a good opportunity for P-RNs to explore the causes of emotional trauma, share personal coping strategies, and where to get support in the CLE, HEI and after work. Self-directed/regulated learning could be promoted by encouraging P-RNs to write personal objectives and engage in recommended reading about last offices and diseases relevant to each clinical placement to prepare them for changes in the patient's condition. In the second year learning about EOLC could be augmented by small groups of P-RNs learning through PBL case studies, cinemeducation and board games, such as 'Seasons of Loss,' to explore empathy. This could be further developed during the third year modules to explore sudden unexpected death and how their role in EOLC changes as a RN.

In addition the HEI can develop strategies to help P-RNs learn the skills of communicating with patients and relatives. In the first year nurses could learn techniques to respond to patients or relatives distress through workshops such as SAGE and THYME (Connolly et al 2010). Second year students could build on this by attending simulations of peaceful death conversations with family members. Final year P-RNs can then explore challenging conversations following an unexpected death in preparation for being a RN. Key during these workshops/simulations would be the opportunity to reflect upon the experience to enhance learning.

A further recommendation is to promote the support of P-RNs in the CLE. This could be through including a session exploring strategies mentors can use to



provide emotional support to P-RNs during EOLC in the mentorship module and annual mentor updates. In addition the personal tutor can also support P-RNs during and after a placement to include reflection upon learning and exploring strategies to manage the emotional impact of EOLC. However, these can be challenging conversations that require a skilled practitioner and therefore, some lecturers may require training to guide P-RNs learning from their clinical experiences (Fabricius 1995, Allan 2011).

In this study P-RNs were active learners and therefore, could be given the opportunity to co-design their curriculum as recommended by Hargreaves (2006). This could be achieved through student representatives collating student's opinions about the EOLC content of the curriculum and written evaluations for each module. These comments can be discussed with the BSc programme design team and where possible, integrated into the curriculum. This has the risk, however, of P-RNs focusing upon personal concerns that may not be shared by the majority, and requesting strategies that cannot be included due to limited time and clinical placements. Nevertheless these could also enhance the delivery of EOLC and sensitive communication. It would also empower the P-RN to co-construct their learning rather than being merely recipients of a curriculum devised by the HEI.

There are recommendations for EOL education in the undergraduate curriculum in USA (AACN 2007), Europe (De Vliegner et al 2004b) and Australia (Australian Government Department of Health 2014). However there are no explicit guidelines in England. Therefore the final recommendation is for the development of national curriculum guidelines to ensure consistent content in EOLC are delivered in each HEI.

### **Recommendations for clinical practice**

The findings from this study have a number of practical implications as mentors have a major influence on workplace learning. LACDP (2014), NICE (2015) and NCPC (2016) all advise Chief Nurses and Trust Managers to enable a culture of compassionate EOLC that puts the recommendations in 'One Chance to Get it Right' (LACDP 2014) and 'Care of Dying Adults in the Last Days of Life' (NICE 2015) into practice. However just telling people to change does not necessarily mean this will happen; therefore the following recommendations are made:

To enable RNs to be life-long learners NHS Trusts could devise an induction workshop to provide training in EOLC and communication for new RNs. In addition, RNs could be given the opportunity to shadow palliative care nurses to observe sensitive communication in practice. This learning can continue through update workshops as part of annual mandatory training. On-going links could be made between theory and practice among RNs by attending Schwartz Centre Rounds group reflections (Goodrich 2011).

It is recommended that RM/Ms translate learning EOLC for P-RNs through learning conversations during which mentors and P-RNs identify gaps in knowledge, co-create learning objectives and discuss the rationale for decisions made. In addition RM/Ms could coach P-RNs during the performance of last offices and CPR and through reflection following these events. This would provide an opportunity for mentors to give feedback on P-RNs' progress, strengths and areas to develop to enhance self-efficacy and promote self-regulated learning to enhance their future development of EOLC skills.

The final recommendation is that mentors recognise the potential emotional impact upon P-RNs and share their strategies for managing emotions while demonstrating compassionate EOLC. Strategies included acknowledging the P-RN's distress, offering time away from the situation and providing the opportunity for P-RNs to reflect upon this with mentors during a learning conversation. To achieve this RNs require access to support and guidance through debrief with experienced exceptional RM/Ms and link lecturers to reflect upon developing their role to support P-RNs.

### **Future research**

The research studies outlined below would contribute to a better understanding of the complex linkages between factors that inhibit and enhance P-RNs learning EOLC:

1. *A longitudinal cohort study following pre-registration nurses learning EOLC during their three year programme, six months and twelve months following registration.*

The proposed study would follow a group of P-RNs throughout the three year programme in a similar way to the current study. Although Kiger (1994) followed a cohort, she did not explore how P-RNs learned

knowledge, skills and to manage their emotions throughout the programme and after registration. Therefore, a study that compares pre-registration knowledge to that at six months and 12 months after qualification may reveal how knowledge is translated into EOLC.

2. *Evaluate the effect of pre-registration nurses' education upon their knowledge, skills and attitudes towards EOLC.*

This study has revealed the lack of evidence in England regarding the effectiveness of education programmes in EOLC. Therefore a study that evaluates the theoretical component would contribute to the body of evidence in England.

3. *Explore mentors perceptions of the effectiveness of supporting pre-registration nurses following death of a patient.*

This thesis revealed learning is enhanced when a mentor values the P-RN as an individual learner. Therefore the findings from this study can contribute towards developing a survey for distribution to mentors to reveal their issues about teaching the knowledge and skills of EOLC and the emotional support of P-RNs. These findings can then be used to develop a workshop or online learning package for mentors to enhance their skills to support P-RNs.

## References

- AACN (2000) *ELNEC End of Life Nursing Education Consortium*. American Association of Colleges of Nursing. Washington DC.
- AACN (2004a) *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*. American Association of Colleges of Nursing, Washington DC.
- AACN (2004b) *Evaluation of ELNEC Training Program Show Growing National Commitment to Strengthening Nursing Care*. American Association of Colleges of Nursing. Washington DC.
- AACN (2007) *End-of-Life Nursing Education Consortium. (ELNEC) Fact Sheet*. American Association of Colleges of Nursing. Washington DC. Retrieved from <http://www.aacn.nche.edu/elneec/FactSheet.pdf> on 20 July 2014.
- AACN (2014) *Essential of Baccalaureate Education for Professional Nursing Practice*. American Association of Colleges of Nursing, Washington DC. USA.
- Ablett J.R. & Jones R.S.P. (2007) Resilience and well-being in palliative care staff: a qualitative study of hospice nurses' experience of work. *Psycho-oncology* **16**(8), 733-740.
- Agar M. & MacDonald J. (1995) Focus groups and ethnography. *Human Organization* **54**(1), 78–86.
- Allan H.T., Smith P.A. & O'Driscoll M. (2008) *Leadership for Learning Final Report*. Retrieved from <https://www.surrey.ac.uk/fhms/research/centres/crnme/Completed%20Projects/Reports/GNC%20main%20report%2022%2005%2008PAS.pdf> on 7 April 2015.
- Allan H.T., Smith P. & O'Driscoll M.F. (2011) Experiences of supernumerary status and the hidden curriculum in nursing: a new twist in the theory-practice gap. *Journal of Clinical Nursing* **20**(5-6), 847-855.
- Allan H.T. (2011) Using psychodynamic small group work in nurse education: closing the theory-practice gap. *Nurse Education Today* **31**(5), 521-524.
- Allchin L. (2006) Caring for the dying: nursing student perspectives. *Journal of Hospice and Palliative Nursing* **8**(2), 112-117.
- Alexander M. & Wasman D. (2000) Cinemeducation: Teaching family systems through the movies. *Families, Systems and Health* **18**(4), 455-467.
- Arber A. (2001) Student nurses' knowledge of palliative care: evaluating and education module. *International Journal of Palliative Nursing* **7**(12), 597-603.
- Attree M. (2001) Patients and relatives experiences and perspective of 'Good' and 'Not so Good' quality care. *Journal of Advanced Nursing* **33**(4), 456-466.

- Atkins S., Lewin S., Smith H., Engel M., Fretheim A. & Volmink J. (2008) Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Medical Research Methodology* **8**, **21** 1-10. Retrieved from <http://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-8-21> on 1<sup>st</sup> November 2010.
- Australian Government Department of Health (2014) *PCC4U Palliative Care Curriculum for Undergraduates*. Queensland University of Technology, Queensland. Retrieved from <http://www.pcc4u.org/> on 14 June 2014.
- Ball J & Pike G (2009) *Past Imperfect, Future Tense: Nurses' Employment and Morale in 2009*. RCN, London.
- Bandura A. (1986) *Social Foundations of Thought and Action: A Social-Cognitive Theory*. Prentice-Hall, Englewood Cliffs.
- Bandura A. (1997a) *Self-Efficacy: The Exercise of Control*. W H Freeman, New York.
- Bandura A. (1997b) *Social Learning Theory*. Prentice-Hall, Englewood Cliffs, New Jersey.
- Bandura A. & Walters R.H. (1969) *Social Learning and Personality Development*. Holt, Rinehart and Winston, London.
- Barbour R.S. & Barbour M. (2003) Evaluating and synthesizing qualitative research: the need to develop a distinctive approach. *Journal of Evaluation in Clinical Practice* **9**(2), 179-186.
- Barbour R. & Kitzinger J. (1999) *Developing Focus Group Research*. Sage, London.
- Barnett-Page E. & Thomas J. (2009) Methods for the synthesis of qualitative research: as critical review. *BMC Medical Research Methodology* **9**(1), 59-70.
- Barroso J., Gollop C.J., Sandelowski M., Meynell J., Pearce P.F., Collins L.J, (2003) The challenges of searching for and retrieving qualitative studies. *Western Journal of Nursing Research* **25**(2), 153-178.
- Barrere C.C., Durkin A. & LaCoursiere S. (2008) The influence of End-of-Life education on attitudes of nursing students. *International Journal of Nursing Education Scholarship* **5**(1), 1-18.
- Bartlett F.C. (1932) *Remembering a Study in Experimental and Social Psychology*. Macmillan, New York.
- Basch C.E. (1987) Focus group interview: An underutilized research technique from improving theory and practice in health education. *Health Education Quarterly*. **14**(4), 411-448.
- Beaver K., Luker K.A. & Woods S. (2000) Primary care services received during terminal illness. *International Journal of Palliative Nursing* **6**(5), 220-227.
- Beck C. (2011) A metaethnography of traumatic childbirth and its aftermath: amplifying causal looping. *Qualitative Health Research* **21**(3), 301-311.

- Beck C.T. (1997) Nursing students' experiences caring for dying patients. *Journal of Nursing Education* **36**(9), 408-415.
- Bell M.L. (1991) Learning a complex nursing skill: student anxiety and the effect of preclinical skill evaluation. *Journal of Nursing Education* **30**(5), 222-226.
- Bengtsson M. & Ohlsson B. (2010) The nursing and medical students motivation to attain knowledge. *Nurse Education Today* **30**(2), 150-156.
- Benner P. (1984) *From Novice to Expert*. Addison-Wesley, Reading.
- Benner, P. (2004). Using the Dreyfus model of skill acquisition to describe and interpret skill acquisition and clinical judgment in nursing practice and education. *Bulletin of Science, Technology & Society*, **24**(3), 188-199.
- Benner P & Wruble J. (1989) *The Primacy of Caring: Stress and Coping in Health and Illness*. Addison-Wesley, Menlo Park.
- Berragan L. (2014) Learning nursing through simulation: a case study approach towards an expensive model of learning. *Nurse Education Today* **34**(8), 1143-1148.
- Bergen A. (1992) Evaluating nursing care of the terminally ill in the community: a case study approach. *International Journal of Nursing Studies* **29**(1), 81-94.
- Biggs J. & Tang C. (2007) *Teaching for Quality Learning at University*. Society for Research into Higher Education & Open University Press, Maidenhead.
- Bland A.J., Topping A. & Wood B. (2011) A concept analysis of simulation as a learning strategy in the education of undergraduate nursing students. *Nurse Education Today* **31**(7), 664-670.
- Bland A.J., Topping A. & Tobbell J. (2014) Time to unravel the conceptual confusion of authenticity and fidelity and their contribution to learning within simulation-based nurse education. A discussion paper. *Nurse Education Today* **34**(7), 1112-1118.
- Booth A. (2008) Unpacking your literature search toolbox: on search styles and tactics. *Health Information & Libraries Journal* **25**(4), 313-317.
- Bowen G.A. (2006) Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods* **5**(3), 12-23.
- Bowen G.A. (2008) Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research* **8**(1), 137-152.
- Bradbury-Jones C., Irvine F. & Sambrook S. (2010a) Empowerment of nursing students in clinical practice: spheres of influence. *Journal of Advanced Nursing* **66**(9), 2061-2070.
- Bradbury-Jones C. & Alcock J. (2010b) Nursing students as research participants: A framework for ethical practice. *Nurse Education Today* **30**(2), 192-196.

Bradbury-Jones C., Sambrook S. & Irvine F. (2011) Empowerment and being valued: phenomenological study of nursing students experiences of clinical practice. *Nurse Education Today* **31**(4), 368-372.

Bradley E.H., Cicchetti D.V., Fried T.R., Rousseau D.M., Johnson-Hurzeler R., Kasl S.V. & Horwitz S.M. (2000) Attitudes about care at the end of life among clinicians: A quick reliable and valid assessment instrument. *Journal of Palliative Care* **16**(1), 6-14.

Brice A. & Carlson C. (2004) The contribution of evidence based practice to educational activities. In *Evidence-based Practice: a Handbook for Information Professionals* (Booth A. & Brice A. eds), Facet Publishing, London, pp 164-177.

Bridgeman H. & Carr E. (1997) The provision of family-focused palliative care in hospital using the Delphi technique. *Nursing Times Research* **2**(6), 443-452.

Bringer D., Johnston L.H. & Brackenridge C.H. (2004) Maximising transparency in a doctorate thesis one: the complexities of writing about the use of QRS\*NVIVO within a grounded theory study. *Qualitative Research* **4**(2), 247-265.

Bringer D., Johnston L.H. & Brackenridge C.H. (2006) Using computer assisted qualitative data analysis software to develop a grounded theory project. *Field Methods* **18**(3), 245-266.

Britten N., Campbell R., Pope C., Donovan J., Morgan M. & Pill R. (2002) Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services & Research Policy* **7**(4), 209-215.

Brotherson M. J. (1994) Interactive focus group interviewing: a qualitative research method in early intervention. *Topics in Early Childhood Special Education* **14**(1), 101-118.

Brookfield S. (1987) *Developing Critical Thinkers. Challenging Adults to Think of Alternative Ways of Thinking and Acting*. Open University Press, Milton Keynes.

Broudy H.S., Smith B.D. & Burnett J (1964) *Democracy and Excellence in American Secondary Education*. Rand McNally, Chicago.

Buchler J. (1961) *The Concept of Method*. Columbia University Press, New York.

Buckman R.A. (2005) Breaking bad news: the SPIKES strategy. *Community Oncology* **2**(2), 138-142.

Bulman C. & Schutz S. (2013) *Reflective Practice in Nursing: the Growth of the Professional Practitioner*. John Wiley and Son, Chichester.

Burt J., Shipman C., Richardson A., Ream A. & Addington-Hall J. (2010) The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives. *Age and Ageing* **39**(1), 86-91.

Byers P.Y. & Wilcox J. R. (1991) Focus groups: A qualitative opportunity for researchers. *Journal of Business Communication* **28**(1), 63-77.

- Calder B.J. (1977) Focus groups and the nature of qualitative marketing research. *Journal of Marketing Research* **14** (3), 353-363.
- Campbell D.T. & Stanley J.C. (1963) *Experimental and Quasi Experimental Designs for Research*. Rand McNally & Company, Chicago.
- Campbell R., Pound P., Pope C., Britten N., Pill R., Morgan M. & Donovan J. (2003) Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine* **56**(4), 671-684.
- Carey A.M. & Smith M.W. (1994) Capturing the group effect in focus groups: A special concern in analysis. *Qualitative Health Research* **4**(1), 123-127.
- Catterall M. & MacLaran P. (1997) Focus group data and qualitative analysis programs. Coding for the moving picture as well as the snapshots. *Sociological Research Online* **2**(1) Retrieved from <http://www.socresonline.org.uk/2/1/6.html> on 11 May 2016.
- Charney D.S. (2004) Psychobiological mechanisms of resilience and vulnerability: implications for successful adaptation to extreme stress. *The American Journal of Psychiatry* **161**(2), 195-216.
- Charmaz K. (2006) *Constructing Grounded Theory*. Sage, London.
- Carpenter J., Stevenson B. & Carson E. (2008) Creating a shared experience: using movies in nursing education. *Nurse Educator* **33**(3), 103-104.
- Cheung R.Y. & Au T.K. (2011) Nursing students' anxiety and clinical performance. *Journal of Nursing Education* **50**(5), 286-289.
- Chesser-Smyth P.A. (2005) The lived experiences of general student nurses on their first clinical placement: phenomenological study. *Nurse Education in Practice* **5**(6), 320-327.
- Clark D. (1995) Cradle to the grave, terminal care in the United Kingdom 1948-1967. *Mortality* **4**(3), 225-247.
- Clark D. & Wright M. (2007) The International Observatory on End-of-Life Care: A global view of palliative care development. *Journal of Pain and Symptom Management* **33**(5), 542-546.
- Clouder L. (2003) Becoming professional: exploring the complexities of professional socialization in health social care. *Learning in Health and Social Care* **2**(4), 213-222.
- Cohen L., Manion L. & Morrison K. (2011) *Research Methods in Education*. 7<sup>th</sup> ed. Routledge, London.
- Collaizzi P. (1978) Psychosocial research as a phenomenologist views it. In *Existential Phenomenological Alternative for Psychology* (Valle B. & King M. eds.), Oxford University Press, Oxford.
- Collett-Lester (1969) Collett-Lester fear of death and fear of dying. *Journal of Psychology* **72**(2), 179-181.



Connelly M., Perryman J., McKenna Y., Orford J., Thomson L., Shuttleworth J. & Cocksedge S. (2010) SAGE & THYME: a model for training health and social care professionals in patient-focussed support. *Patient Education and Counseling* **79**(1), 87-93.

Cooke A., Smith D. & Booth A. (2012) Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research* **22**(10), 1435-1443.

Cooper J. & Barnett M. (2005) Aspects of caring for dying patients which cause anxiety to first year student nurses. *International Journal of Palliative Nursing* **11**(8), 423-430.

Corfman K.P. (1995) The importance of member homogeneity to focus group quality. *Advances in Consumer Research* **22**(2), 354-359.

Corner J., Clark D. & Normand C. (2002) Evaluating the work of clinical nurse specialist in palliative care. *Palliative Medicine* **16**(2), 275-277.

Corner J. & Wilson Barnett J. (1992) The newly registered nurse and the cancer patient: an educational evaluation. *International Journal of Nursing Studies* **29**(2), 177-190.

Costantini M., Pellegrinii F, Di Leo S., Beccaro M., Rossi C., Flego G., Romoli V., Giannotti M., Morone P., Ivaldi G.P., Cavallo L., Fusco F. & Higginson I.J. (2013) The Liverpool Care Pathway for cancer patients dying in hospital medical wards: a before-after cluster phase II trial of outcomes reported by family members. *Palliative Medicine* **28**(1), 10-17.

Costello J. (2006) Dying well: nurses' experiences of good and bad deaths in hospital. *Journal of Advanced Nursing* **54**(5), 594-601.

Cote-Arsenault D. & Morrison-Beedy D. (2001) Women's voices reflecting changed expectations for pregnancy after perinatal loss. *Journal of Nursing Scholarship* **33**(3), 239-244.

Crombie A., Brindley J., Harris D., Marks-Maran D & Thompson T. (2013) Factors that enhance rates of completion: What makes students stay? *Nurse Education Today* **33**(11), 1282-1287.

Cunningham S.M., Copp G., Collins B & Bater M. (2006) Pre-registration nursing students' experience of caring for cancer patients. *European Journal of Oncology Nursing* **10**(1), 59-67.

Cystic Fibrosis Trust (2011) *Cystic Fibrosis our Focus. Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK*. Cystic Fibrosis Trust, Bromley. Retrieved from <https://www.cysticfibrosis.org.uk/the-work-we-do/clinical-care/consensus-documents> on 13 November 2015.

Damasio A.R. (1996) The somatic marker hypothesis and the possible functions of the prefrontal cortex. *Philosophical Transaction: Biological Sciences* **351**(1346), 1413-1420.

Daniels H. (2005) *An Introduction to Vygotsky*. 2<sup>nd</sup> ed. Routledge, London.

David M. & Sutton C.D. (2004) *Social Research the Basics*. Sage, London.

- Deary J.J., Watson R. & Hogston R. (2003) A longitudinal cohort study of burnout and attrition in nursing students. *Journal of Advanced Nursing* **43**(1), 71-81.
- Degner L.F & Gow C.M. (1988) Evaluations of death education in nursing. *Cancer Nursing* **11**(3), 151-159.
- De Souza J. & Pettifer A. (2013) *End-of-Life Nursing Care: A Guide for Best Practice*. Sage, London.
- De Vlioger M., Gocchs N., Larkin P.J. & Porchet F. (2004a) Palliative nurse education: towards a common language. *European Journal of Palliative Care* **11**(4), 135-138.
- De Vlioger M., Gorchs N., Larkin P.J. & Porchet F. (2004b) *A Guide for the Development of Palliative Nurse Education in Europe. Palliative Nurse Education: report of the EAPC Task Force*. European Association for Palliative Care, Milano Italy. Retrieved from <http://www.eapcnet.eu/LinkClick.aspx?fileticket=e9JnEa7YZDM%3D> on 3 January 2012.
- Dewey J. (1933) *How We Think: A Restatement of the Relation of Reflective Thinking to the Educative Process*. D.C. Heath, Boston.
- DH (2008) *End-of-Life Care Strategy*. The Stationary Office, London.
- DH (2009) *Skills for Health, Skills for Care, NHS End-of-Life Care Programme. Common core competences and principles for health and social care workers working with adults at the end of life*. Department of Health, London. Retrieved from <http://www.skillsforhealth.org.uk/~media/Resource-Library/PDF/EoLC-Core-competences-Guide-Jul2009.ashx> on 10 May 2010.
- DH (2012a) *First National VOICES Survey of Bereaved People*. Department of Health, London. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216894/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216894/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf) on 5 January 2013
- DH (2012b) *Compassion in Practice. Nursing, Midwifery and Care Staff: Our Vision and Strategy*. Department of Health, London. Retrieved from <http://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf> on 20 January 2013.
- DH (2013) *More Care Less Pathway: a Review of the Liverpool Care Pathway*. Department of Health, London Retrieved from <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients> on 5 May 2013.
- Di Bartolo M.C. & Seldomridge L.A. (2009) Cinemeducation teaching end-of-life issues using feature films. *Journal of Gerontological Nursing* **35**(8), 30-36.
- Dickinson G.E., Clark D. & Sque M. (2008) Palliative care and end of life issues in UK pre-registration, undergraduate nursing programmes. *Nurse Education Today* **28**(2), 163-170.

- Dickson-Swift V., James E.L., Kippen S. & Liamputtong P. (2008a) *Undertaking sensitive research in the Health and Social Sciences*. Cambridge University Press, Cambridge.
- Dickson-Swift V., James E.L., Kippen S. & Liamputtong P. (2008b) Risk to researchers in qualitative research on sensitive topics: issues and strategies. *Qualitative Health Research* **18**(1), 133-144.
- Dixon-Woods M., Andrew B. & Smith J.A. (2007) Synthesizing qualitative research: a review of published reports. *Qualitative Research* **7**(3), 375-422.
- Dixon-Woods M., Shaw R.L., Agarwal S. & Smith J.A. (2004) The problem of appraising qualitative research. *Quality and Safety in Health Care* **13**(3), 223-225.
- Dobbins E.H. (2011) The impact of end-of-life curriculum content on the attitudes of associate degree nursing students towards death and care of the dying. *Teaching and Learning in Nursing* **6**(4), 159-166.
- Donaldson J.H. & Carter D. (2005) The value of role modelling: perceptions of undergraduate diploma nursing (adult) students. *Nurse Education in Practice* **5**(6), 353-359.
- Donovan J. (1995) The process of analysis during a grounded theory study of men during their partners' pregnancies. *Journal of Advanced Nursing* **21**(4), 708-715.
- Doyle L.H. (2003): Synthesis through meta-ethnography: paradoxes, enhancements and possibilities. *Qualitative Research* **3**(3), 321-344.
- Doyle S. (2013) Reflexivity and the capacity to think. *Qualitative Health Research* **23**(2), 248-255.
- Dreyfus S.E. & Dreyfus H.L. (1980). *A Five-Stage Model of the Mental Activities Involved in Directed Skill Acquisition*. Storming Media, Washington, DC.
- Duggleby W. (2005) What about focus group interaction data? *Qualitative Health Research* **15**(6), 832-840.
- Dunn R. (2012) Exploring the influences of students' attributions for success on their self-regulation in pathophysiology. *Journal of Nursing Education* **51**(6), 353-359.
- Dunne K. & Sullivan K. (2000) Family experiences of palliative care in the acute hospital setting. *International Journal of Palliative Nursing* **6**(4), 170-178.
- Dunne K., Sullivan K. & Kernohan G. (2005) Palliative care for patients with cancer: district nurses' experiences. *Journal of Advanced Nursing* **50**(4), 372-380.
- Eakin J.M. & Mykhalovskiy E. (2003) Reframing the evaluation of qualitative health research: reflections on a review of appraisal guidelines in the health sciences. *Journal of Evaluation in Clinical Practice* **9**(2), 187-194.

Eaves Y.D. (2001) A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing* **35**(5), 654-663.

Ellershaw J. & Wilkinson S. (2003) *Care of the Dying*. Oxford University Press, Oxford.

Entwistle N. (2009) *Teaching for Understanding at University: Deep Approaches and Distinctive Ways of Thinking*. Palgrave Macmillan, Basingstoke.

EONS (1994) *Report and Recommendations of a Workshop to Study the Feasibility of Educational Programmes in Palliative Care for Nurses in Europe*. EONS, Dublin.

Eraut M, (1985) Knowledge creation and knowledge use in professional context. *Studies in Higher Education* **10**(2),117-133.

Eraut M. (1994) *Developing Professional Knowledge and Competence*. The Falmer Press, London.

Eraut M. (2000) Non-formal learning and tacit knowledge in professional work. *British Journal of Educational Psychology* **70** (1), 113-136.

Eraut M. (2004a) Transfer of knowledge between the education and workplace, settings. In *Workplace Learning in Context* (Rainbird H., Fuller A. & Munro H. eds.), Routledge, London, pp 201-221.

Eraut M. (2004b) Informal learning in the workplace. *Studies in Continuing Education* **26**(2), 247-273.

Eraut M. (2007a) Learning from other people in the workplace. *Oxford Review of Education* **33**(4),403-422.

Eraut M. (2007b) Early career learning at work and its implications for universities. In *Student Learning and University Teaching The British Education Psychological Monograph Series II number 4*. (Entwistle N. & Tomlinson P. eds.), The British Psychological Society, London pp 113-133.

Eraut M. (2012) Developing a broader approach to professional learning. In *Learning Trajectories, Innovation and Identity for Professional Development*. (McKee A. & Eraut M. eds.), Springer, London, pp.21-45.

Estabrooks C.A., Field P.A. & Morse J.M. (1994) Aggregating Qualitative Findings: An Approach to Theory Development. *Qualitative Health Research* **4**(4), 503-511.

Evans K. (2004) Recognition of tacit skills: sustaining learning outcomes in adult learning and work re-entry. *International Journal of Training and Development* **8**(1), 54-72.

Evans K., Guile D., Harris J. & Allen H. (2010) Putting knowledge to work: A new approach. *Nurse Education Today* **30**(3), 245-251.

- Evans W. & Kelly B. (2004) Pre-registration diploma student nurse stress and coping measures. *Nurse Education Today* **24**(6), 473-482.
- Fabricius J. (1991a) Learning to work with feelings-psychodynamic understanding and small group work with junior student work. *Nurse Education Today* **11**(2), 134-147.
- Fabricius J. (1991b) Running on the spot or can nursing really change. *Psychoanalysis Psychotherapy* **5**(2), 97-108.
- Fabricius J. (1995) Psychoanalytic understanding and nursing: A supervisory workshop with nurse tutors. *Psychoanalytic Psychotherapy* **9**(1), 17-29.
- Fabricius J. (1999) The crisis in nursing. Reflection on the crisis. *Psychoanalysis Psychotherapy*. **13**(3), 203-206.
- Faculty of Intensive care Medicine/The Intensive Care Society (2013) *Core Standards for Intensive Care Units*. Retrieved from [https://www.ficm.ac.uk/sites/default/files/Core%20Standards%20for%20ICUs%20Ed.1%20\(2013\).pdf](https://www.ficm.ac.uk/sites/default/files/Core%20Standards%20for%20ICUs%20Ed.1%20(2013).pdf) on 11 November 2015.
- Falk K., Falk H. & Jakobsson Ung E. (2016) When practice precedes theory- A mixed methods evaluation. *Nurse Education in Practice* **16**(1), 14-19.
- Fern E.F. (1982) The use of focus groups for idea generation: The effects of group size, acquaintanceship and moderator on response quantity and quality *Journal of Marketing Research* **19**(2), 1-13.
- Field D. & Copp G. (1999) Communication and awareness about dying in the 1990's. *Palliative Medicine* **13**(6), 459-468.
- Finch H. & Lewis J. (2003) Focus Groups. In *Qualitative Research Practice: a guide for social science students and researchers* (Ritchie J. & Lewis J. eds.), Sage, Los Angeles, pp 170-199.
- Finfgeld D.L. (2003) Metasynthesis: the state of the art so far. *Qualitative Health Research* **13**(7), 893-904.
- Finfgeld-Connett D. (2006) Meta-synthesis of presence in nursing. *Journal of Advanced Nursing* **55**(6), 708-714.
- Finfgeld-Connett D. (2010) Generalizability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing* **66**(2), 246-254.
- Finlay L. (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research. *Qualitative Research* **2**(2), 209-230.
- Finlay L. & Gough B. (2003) *Reflexivity. A Practical Guide for Researchers in Health and Social Sciences*. Blackwell Publishing, Oxford.
- Fluharty L., Hayes A.S., Milgrom L., Malrney K., Smith D., Reklau M.A., Jeffries P. & McNelis A.M. (2012) A multisite, multi-academic track evaluation of End-of-Life simulation for nursing education. *Clinical Simulation in Nursing* **8**(4), 135-143.

- Foronda C., Gattamorta K., Snowden K. & Bauman E.B. (2014) Use of virtual clinical simulation to improve communication skills of baccalaureate nursing students: A pilot study. *Nurse Education Today* **34**(6), 53–57.
- Fothergill-Boubonnais F. & Wilson-Barnett J. (1992) A comparative study of intensive therapy unit and hospice nurses' knowledge on pain management. *Journal of Advanced Nursing* **17**(3), 362-372.
- Freshwater D. & Stickley T.J. (2004) The heart of art: emotional intelligence in nurse education. *Nursing Inquiry* **11**(2), 91-98.
- Frommelt K.H.M. (1991) The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. *American Journal of Hospice & Palliative Care* **7**(5), 37-43.
- Fulton J.A. (2008) Strategies used by nurses when managing the emotional needs of patients. *Learning in Health and Social Care* **7**(3), 157-167.
- Gersie A. (1991) *Story Telling in Bereavement: Dragons Fight in the Meadow*. Jessica Kingsley, London.
- Gibbs G. (2002) *Qualitative Data Analysis: Explorations with NVivo*. Open University Press, Buckingham.
- Gillan P.C., Jeong S. & van der Reit P.J. (2013a) End-of-life care simulation: A review of the literature. *Nurse Education Today* **33**(11), 766-774.
- Gillan P.C., Parmenter G., Van de Riet P.J. & Jeong S. (2013b) The experience of end-of-life care simulation at a rural Australian University. *Nurse Education Today* **33**(11), 1435-1439.
- Giorgi A.P. & Giorgi B.M. (2003) The descriptive phenomenological psychological method. In *Qualitative Research in Psychology Expanding Perspectives in Methodology and Design* (Carnic P.M., Rhodes J.E. & Yardley L. eds.), American Psychological Association, pp 243-273.
- Glaser B. & Strauss A. (1965) *Awareness of Dying*. Aldine, Chicago.
- Glaser B. & Strauss A.L. (1967) *Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldien Publishing, New York.
- GMC (2010) *Treatment and Care Towards the End of Life*. GMC, London Retrieved from [http://www.gmc-uk.org/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_lifeEnglish\\_0414.pdf\\_48902105.pdf](http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_lifeEnglish_0414.pdf_48902105.pdf) on 6 July 2014
- Goleman D. (2001) An EI-based theory of performance. In *The Emotional Intelligent Workplace: How to Select for Measure and Improve Emotional Intelligence in Individual Groups and Organisations* (Cheniss C. & Goleman D eds.), Jossey-Bass, San Francisco, pp 27-44.
- Gomersall T., Madill A. & Summers L. (2011) A metasynthesis of the self-management of type 2 diabetes. *Qualitative Health Research* **21**(6), 853-871.
- Goodrich J. (2011) *Schwartz Centre Rounds. Evaluation of the UK Pilots*. Kings Fund, London.

- Greenhalgh T., Robert G., Macfarlane F., Bate P., Kyriakidou O. & Peacock R. (2005) Storylines of research in diffusion of innovation: a meta-narrative approach to systematic review. *Social Science and Medicine* **61**(2), 417-430.
- Greenhalgh T. (2010) *How to Read a Paper: the Basics of Evidence-based Medicine*. Wiley-Blackwell, Chichester.
- Greenwood N., Ellmers T. & Holley J. (2014) The influence of ethnic groups composition on focus group discussions. *BMC Medical Research Methodology* **14**(107), 1-13.
- Griggs C. (2010) Community nurses' perceptions of a good death: a qualitative exploratory study. *International Journal of Palliative Nursing* **16**(3), 139-148.
- GSF (2010) *Gold Standards Framework*. Retrieved from <http://www.goldstandardsframework.nhs.uk> on 20 April 2013.
- GSF (2012) *Gold Standard Framework Acute Hospitals Programme January 2012*. Retrieved from <http://www.goldstandardsframework.org.uk/GSFAH> on 6 July 2013
- Guba E.G. & Lincoln Y.S. (1989) *Fourth Generation Evaluation* Sage, Newbury.
- Guile D. & Evans K. (2010) Putting Knowledge to Work: re-contextualising knowledge through the design and implementation of work-based learning at higher education levels. *Innovating Workforces Development*, Foundation Degree Forward Higher Education Academy. Retrieved from <https://www.heacademy.ac.uk/sites/default/files/putting-knowledge-to-work.pdf> on 1<sup>st</sup> November 2015.
- Hamill C. (1995) The phenomenon of stress as perceived by Project 2000 student nurses: a case study. *Journal of Advanced Nursing* **21**(3), 528-536.
- Hamilton C.A. (2010) The simulation imperative of end of life education. *Clinical Simulation in Nursing* **6**(4), 131-138.
- Hargreaves D.H. (2006) *A new shape for schooling?* Specialist Schools and Academies Trust. Retrieved from [http://complexneeds.org.uk/modules/Module-3.2-Engaging-in-learning---key-approaches/D/downloads/m10p020d/a\\_new\\_shape\\_for\\_schooling\\_1.pdf](http://complexneeds.org.uk/modules/Module-3.2-Engaging-in-learning---key-approaches/D/downloads/m10p020d/a_new_shape_for_schooling_1.pdf) on 14th November 2015.
- Herbig, B., Bussing A., Ewert T. (2001) The role of tacit knowledge in the work context of nursing. *Journal of Advanced Nursing* **34**(5), 687-695.
- Higgins G., Spencer R.L. & Kane R. (2006) A systematic review of the experiences and perceptions of the newly qualified nurse in the United Kingdom. *Nurse Education Today* **30**(6), 499-508.
- Higginson I. (2003) *Priorities and Preference for End-of-Life Care in England Wales and Scotland*. NCPC, London.
- Hinton R.R., McMurray I. & Brownlow C. (2014) *SPSS Explained*. 2<sup>nd</sup> ed. Routledge, London.

- HM Government (2003) *Data Protection Act 2003*. Retrieved from <https://www.gov.uk/data-protection/the-data-protection-act> on 20 May 2011.
- Hmelo-Silver C.E. (2004) Problem-Based Learning: What and How Do Students Learn? *Educational Psychology Review* **16**(3), 235-266.
- Hospital Episode Statistics (2015) *Hospital Episode Statistics 2013-2014*. Health and Social Care Information Centre, London. Retrieved from <http://www.hscic.gov.uk/catalogue/PUB16719/hosp-epis-stat-admi-summ-rep-2013-14-rep.pdf> on 15 April 2016.
- Hopkinson J.B., Hallett C.E & Luker K.A. (2003) Caring for dying people in hospital. *Journal of Advanced Nursing* **44**(5), 525-533.
- Howard E., Hubelbank J. & Moore P. (1989) Employer evaluation of graduates: use focus group. *Nurse Educator* **14**(5), 38-41.
- Humphreys C. (2001) "Waiting for the last summons": the establishment of the first hospices in England 1878-1914. *Mortality* **6**(2), 146-166.
- Hydén L.C. & Bülow P.H. (2003) Who's talking: drawing conclusions from focus groups—some methodological considerations *International Journal of Social Research Methodology* **6**(4), 305-321.
- James N. (1992) Care = organisation + physical labour + emotional labour. *Sociology of Health and Illness* **14**(4), 488-505.
- Jayasekara R.S. (2012) Focus groups in nursing research: Methodological perspectives. *Nursing Outlook* **60**(6), 411-416.
- Jensen L. A. Allen M. N. (1996) Meta-synthesis of qualitative findings. *Qualitative Health Research* **6**(4), 553-560.
- Johnson G.R. (1994) The phenomenon of death: a study of Diploma in Higher Education nursing students' reality. *Journal of Advanced Nursing* **19**(6), 1151-1161.
- Johnson B. & Smith L.N. (2006) Nurses' and patients' perceptions of expert palliative nursing care. *Journal of Advanced Nursing* **54**(6), 700-709.
- Jordan A., Carlile O. & Stack A. (2008) *Approaches to Learning: A Guide for Teachers*. McGraw-Hill Open University Press, Maidenhead.
- Kearney M.H. (2001) Enduring love: a grounded formal theory of women's experience of domestic violence. *Research in Nursing and Health* **24**(4), 270-282.
- Keeling J. & Templeman J. (2013) An exploratory study: student nurses perceptions of professionalism. *Nurse Education in Practice* **13**(1), 18-22.
- Kelly G. (1955) *The Psychology of Personal Constructs*. Roulledge, London.
- Kevern J. & Webb C. (2004) Mature women's experiences of pre-registration nurse education. *Journal of Advanced Nursing* **45**(3), 297-306.



- Kiger A.M. (1993) Accord and discord in students images of nursing. *Journal of Nursing Education* **3**(27), 309-317.
- Kiger A.M. (1994) Student nurses' involvement with death: the image and the experience. *Journal of Advanced Nursing* **20**(4), 679-686.
- Kitzinger J. (1994) The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health* **16**(1), 103-121.
- Knowles M. (1990) *The Adult Learner: A Neglected Species*. Gulf Publishing, Houston.
- Kolb D.A. (1984) *Experiential Learning: Experience As the Source of Learning and Development*. Prentice-Hall, Englewood Cliffs.
- Kopp W. & Hanson M.A. (2012) High-fidelity and gaming simulations enhance nursing education in end-of-life-care. *Clinical Simulation in Nursing* **8**(3), 97-102
- Koufogiannakis D., Booth A. & Brettle A. (2006) ReLIANT Readers guide to the Literature on Interactions Addressing the Need for education and Training. *Library and Information Research* **30**(94), 4-51.
- Krueger R.A. (1998) *Focus Group Kits 1-6*. Sage, Thousand Oaks, Cal.
- Krueger R.A. & Casey M.A. (2009) *Focus Groups: a Practical Guide for Applied Research*. 4<sup>th</sup> ed. Sage, Los Angeles.
- Krueger R.A. & Casey M.A. (2015) *Focus Group: A Practical Guide for Applied Research*. 5<sup>th</sup> ed. Sage, Thousand Oaks.
- Kubler-Ross E. (1970) *On Death and Dying*. Routledge, London.
- Kuiper R., Murdock N. & Grant N. (2010) Thinking strategies of Baccalaureate nursing students prompted by self-regulated learning strategies. *Journal of Nurse Education* **49**(8), 425-436.
- Kwekkeboom K.L., Vahl C. & Eland J. (2005) Companionship and education: A nursing student experience in palliative care. *Journal of Nursing Education*. **44**(4), 169-176.
- Kwekkeboom K.L., Vahl C. & Eland J. (2006) Impact of a volunteer companion program on nursing students' knowledge and concerns related to palliative care. *Journal of Palliative Medicine* **9** (1), 90-99.
- LACDP (2014) *One Chance to Get It Right. Improving People's Experience of Care in the Last Few Days and Hours of Life*. LACDP Publications Gateway Reference 01509 Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/323188/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf) on 8 July 2014
- Ladd C., Grimley K., Hickman C. & Touhy T.A. (2013) Teaching end-of-life nursing simulation. *Journal of Hospice and Palliative Nursing* **15**(1), 41-51.
- Langridge M.E. & Hauck Y.L. (1998) Perception of clinical role modelling: an exploration of nursing students' experiential learning. *Collegian* **5**(4), 22-27.

- Laster K. (2007) High fidelity simulation and the development of clinical judgement students experiences. *Journal of Nursing Education* **46**(6), 269-276.
- Lave J. & Wenger E. (1991) *Situated Learning Legitimate Peripheral Participation*. Cambridge University Press, Cambridge.
- Lawler J. (1991) *Behind the Screens. Nursing Somology and the Problem of the Body*. Churchill Livingstone, Edinburgh.
- Lawton J. (2000) *The Dying Process*. Routledge, London.
- LeBlanc V.R., Redehr C., Tavares E., Scott A.K., MacDonald R. & King K. (2012) The impact of stress on paramedic performance during simulated critical events. *Prehospital and Disaster Medicine* **27**(4), 369-374.
- Lee C.M. & Renzetti M.L. (1993) *Researching Sensitive Topics*. Sage, Newbury Park.
- Leigh G.T. (2008) High fidelity patient simulation and nursing students self-efficacy re review of the literature. *International Journal of Nursing Education Scholarship* **5**(1), 1-17.
- Leighton K. & Dubas J. (2009) Simulated death: an innovative approach to teaching end-of-life-care. *Clinical Simulation in Nursing* **5**(6), e223-e230.
- Levett-Jones T.L. (2005) Self-directed learning: implications and limitations for undergraduate nursing education. *Nurse Education Today* **25**(3), 363-368.
- Levett-Jones T. & Lathlean J. (2008) Belongingness: A prerequisite for nursing student clinical learning. *Nurse Education in Practice* **8**(2), 103-111.
- Levett-Jones, T. & Lathlean J. (2009) The Ascent to Competence conceptual framework: an outcome of a study of belongingness. *Journal of Clinical Nursing*, **18**(20), 2870-2879.
- Liamputtong P. (2004) *Focus Group Methodology Principle and Practice*. Sage, Thousand Oaks.
- Lipworth W., Hooker C. & Carter S. (2011) Balance, balancing, and health. *Qualitative Health Research* **21**(5), 714-725.
- Lloyd-Williams M. & Field D. (2002) Are undergraduate nurses taught palliative care during their training? *Nurse Education Today* **22**(5), 589-592.
- Loftus L.A. (1998) Student nurses' lived experience of the sudden death of their patients. *Journal of Advanced Nursing* **27**(3), 641-648.
- Macnaughten P. & Myers G. (2004) Focus groups: The moderator's view and the analyst's view. In *Qualitative Research Practice* (Gobo G. Gubrium C., Seale C. & Silverman D. eds.), Sage, Thousand Oaks, pp 65-79.
- Mallory J.L. (2003) The impact of a palliative care educational component on attitudes toward care of the dying in undergraduate nursing students. *Journal of Professional Nursing* **19**(5), 305-312.

- Marie Curie Cancer Care (2013) *Planning Ahead*. Retrieved from <http://www.mariecurie.org.uk/> on 31 August 2013.
- Marton F. & Saljo R. (1976a) On qualitative differences in learning. Outcome and process. *British Journal of Educational Psychology* **46**(1), 4-11.
- Marton F. & Saljo R. (1976b) On qualitative differences in learning. II Outcome as a function of the learners conception of the task. *British Journal of Educational Psychology* **46**(2), 115-127.
- Maslow A.H. (1970) *Motivation and Personality*. Harper & Row, London.
- Mazor K.M. (2004) Development and Testing of a New Instrument for Measuring Concerns about Dying in Health Care Providers. *Assessment* **11**(3), 230-237.
- Maxwell J.A. (1992) Understanding and validity in qualitative research. *Harvard Educational Review* **63**(3), 279-300.
- McGarth D. Higgins A. (2006) Implementing and evaluating reflective practice group sessions. *Nurse Education in Practice* **63**(6), 175-181.
- McLafferty I. (2004) Focus group interviews as a data collecting strategy. *Journal of Advanced Nursing* **48**(2), 187-194.
- McQueen A.C.H. (2004) Emotional intelligence in nursing work. *Journal of Advanced Nursing* **47**(1), 101-108.
- McSherry W. (2007) *The Meaning of Spirituality and Spiritual Care Within Nursing and Health Care Practice*. Quay Books, London.
- Menzies I. E. P. (1960) A Case-Study in the Functioning of Social Systems as a Defence against Anxiety: A Report on a Study of the Nursing Service of a General Hospital. *Human Relations* **13**(2), 95-121.
- Merton RK, Fiske M.& Kendall P.L. (1990) *The Focused Interview: Manual of Problems and Procedures*. Free Press, New York.
- Meyer J.H. & Land R. (2003) Threshold concepts and troublesome knowledge: linkages to ways to thinking and practicing within the disciplines. In *Improving Student Learning, Theory and Practice-10 years on. Proceedings of the 2003:10<sup>th</sup> International Symposium*. Oxford Centre for Staff and Learning Development, Oxford, pp 412-424.
- Mezirow J. (1985) A critical theory of self-directed learning. *New Directions for Adult and Continuing Education* **1985**(25), 17-30.
- Miles M.B. & Huberman A.M. (1994) *Qualitative Data Analysis*. Sage, Thousand Oaks.
- Miller A. & Bull R.M. (2013) Do you want to play? Factors influencing nurse academics adoption of simulation in their teaching practice. *Nurse Education Today* **33**(3), 241-246.
- Milton I.C. (1984) Concerns of final year baccalaureate students about nursing dying patients. *Journal of Nursing Education* **23**(7), 298-301.

- Moreland S.S., Lemieux M.L. & Myers A. (2012) End-of-life and the use of simulation in a Baccalaureate nursing programme. *International Journal of Nursing Education Scholarship* **9**(1), 1-16.
- Morgan D. L. (1989) Adjusting to widowhood: Do social networks really make it easier? *The Gerontologist* **29**(1), 101-107.
- Morgan D.L. (1997) *Focus Groups As Qualitative Research*. 2<sup>nd</sup> ed Sage, Thousand Oaks.
- Morgan D. L. (2010) Reconsidering the role of interaction in analysing and reporting focus groups. *Qualitative Health Research* **20**(5), 718-722.
- Morgan D.L. (2012) Focus group and social interaction. In *The Sage Handbook of Interview Research* 2<sup>nd</sup> ed. (Gubrium J.F. Holstein J.A. Marvasti A.B. McKinney K.D. eds.), Sage, London, pp161-163.
- Morgan D.L. (2015) From themes to hypothesis: Following up with quantitative methods. *Qualitative Health Research* **25**(6), 789-793.
- Morgan D.L. & Spanish M.T. (1984) Focus groups anew tool for qualitative research. *Qualitative Sociology* **7**(3), 252-270.
- Mullen P.A. (2006) Use of self-regulating learning strategies by students in the second and third trimesters of an accelerated second-degree baccalaureate nursing programme. *Journal of Nursing Education* **46**(9), 406-412.
- NAO (2008) *Survey of Nurses*. National Audit Office, London.
- NCPC (2005a) *Listening to Users*. National Council for Palliative Care. National Council for Palliative Care, London.
- NCPC (2005b) *Improving Palliative Care for Older People in Care Homes*. National Council for Palliative Care, London.
- NCPC (2005c) *20:20 vision: The Shape of the Future for Palliative Care*. National Council for Palliative Care, London.
- NCPC (2006a) *Exploring the Palliative Care Need of People with Dementia*. National Council for Palliative Care, London.
- NCPC (2006b) *National Survey of Heart Failure Nurses and their Involvement with Palliative Care Services*. National Council for Palliative Care, London.
- NCPC (2006c) *Neurological Conditions from Diagnosis to Death-National Survey*. National Council for Palliative Care, London.
- NCPC (2006d) *Changing Gear. Guidelines for Managing the Last Days of Life in Adults*. National Council for Palliative Care, London.
- NCPC (2008) *A Fresh Approach: Palliative and End-of-Life Care for People with Chronic Respiratory Disease*. National Audit Office, London.
- NCPC (2016) *Staff Prepared to Care? Capacity and Competence in the End of Life Care workforce*. NCPC, London.

Neuberger J. (2013) *Snapshot Review of Complaints in End-of-Life Care*. NHS Improving Quality, London Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212480/Review\\_of\\_complaints\\_end\\_of\\_life\\_care.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212480/Review_of_complaints_end_of_life_care.pdf) on 5 August 2013.

NHS (2011) *Guidance for staff responsible for care after death (last offices)* by National End-of-Life-Care Programme and National Nurse Consultant Group (Palliative Care). Retrieved from [http://www.nhs.uk/media/2426968/care\\_after\\_death\\_guidance.pdf](http://www.nhs.uk/media/2426968/care_after_death_guidance.pdf) On 14 March 2014.

NICE (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. National Institute for Clinical Excellence, London. Retrieved from <http://www.nice.org.uk/guidance/index> on 5 February 2012.

NICE (2013) *Quality Standards for End-of-Life Care for Adults*. NICE, London. Retrieved from <http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13> on 14 February 2014

NICE (2015) *Care of Dying Adults in the Last Days of Life*. NICE, London. Retrieved from [nice.org.uk/guidance/ng31](http://www.nice.org.uk/guidance/ng31) on 18 December 2015.

NMC (2004) *Standards of Proficiency for Pre-registration Nurses Education*. Nursing and Midwifery Council, London.

NMC (2007) *Simulation and Practice Learning Project: Outcome of a Pilot Study to Test the Principles for Auditing Simulated Practice Learning Environments in the Preregistration Nursing Programme. Final Report*. Nursing Midwifery Council, London.

NMC (2008a) *Standards to Support Learning and Assessment in Practice: NMC Standards for Mentors, Practice Teachers and Teachers*. Nursing Midwifery Council, London.

NMC (2008b) *Essential Skills Clusters for Pre-registration Nursing Programmes*. Nursing Midwifery Council, London.

NMC (2008c) *The Code: Standards of Conduct, Performance and Ethics for Nurses and Midwives*. Nursing and Midwifery Council, London.

NMC (2010a) *Standards of Proficiency for Pre-registration*. Nursing and Midwifery Council, London.

NMC (2010b) *Changes to Pre-registration Nursing Programmes*. NMC. London Retrieved from <http://www.nmc-uk.org/Get-involved/Consultations/Past-consultations/By-year/Pre-registration-nursing-education-Phase-2/Changes-to-pre-registration-nursing-programmes-FAQs/> on 14 March 2011.

NMC (2010c) *Raising and Escalating Concerns*. Nursing and Midwifery Council, London.

Noblit G.W. & Hare R.D. (1988) *Meta-Ethnography: Synthesising Qualitative Studies*. Sage, Newbury Park.

Noyes J., Popay J., Pearson A., Hannes K., Booth A. & Cochrane Qualitative Research Methods Group (2011) *Qualitative Research and Cochrane Reviews*.

The Cochrane Collaboration, London. Retrieved from: [www.cochrane-handbook.org](http://www.cochrane-handbook.org) on 13 July 2013.

O'Driscoll M.F., Allan H.T. & Smith P.A. (2010) Still looking for leadership- Who is responsible for student nurses' learning in practice? *Nurse Education Today* **30**(3), 212-217.

Oxford English Dictionary (2014) *Oxford English Dictionary Online*. Oxford University Press, Oxford. Retrieved from <http://www.oed.com/view/Entry/166642?redirectedFrom=robotic#eid> on 14 July 2014.

Parliamentary and Health Service Ombudsman (2015) *Dying without Dignity* Parliamentary and Health Service Ombudsman, London.

Paris S. & Paris A. (2001) Constructing theories, identities and actions of self-regulated learning. In *Self-regulated learning and academic achievement: Theoretical perspective* (Zimmerman B.J. & Schunk D.H. eds.), Routledge, New York, pp 253-287.

Parker F.M. & Faulkes D. (2004) Lights, camera, action: using feature films to stimulate emancipatory learning in the RN to BSN students. *Nurse Educator* **29**(4), 144-146.

Parry M. (2011) Student nurses' experience of their first death in clinical practice. *International Journal of Palliative Nursing* **17**(9), 448-453.

Paterson B.L., Thorne S.E., Canam C. & Jillings C. (2001) *Meta-study of Qualitative Health Research: a Practical Guide to Meta-analysis and Meta-synthesis*. Sage Thousand Oaks, Cal.

Pekrun R. (1992) The impact of emotions on learning and achievement: towards a theory of cognitive/motivational mediators. *Applied Psychology: An International Review* **41**(4), 359-376.

Pekrun R., Frenzel A.C., Goetz T. & Perry R.P. (2007) Theoretical perspective on emotions in education. In *Emotion in Education* (Shuntz P.A. & Pekrun R. eds.) Academic Press Elsevier, Burlington, pp 13-37.

Pereira S.M., Fonseca A.M. & Carvalho A.S. (2011) Burnout in palliative care: A systematic review. *Nurse Ethics* **18**(3), 317-326.

Perry B. (2009) Role modelling excellence in clinical nursing practice. *Nurse Education in Practice* **9**(1), 36-44.

Petty J. (2013) Interactive, technology-enhanced self-regulated learning tools in healthcare education: A literature review. *Nurse Education Today* **33**(1), 53-59.

Pike T. & O'Donnell C. (2010) The impact of clinical simulation on learner self-efficacy in pre-registration nursing education. *Nurse Education Today* **30**(5), 405-510.

Polanyi M. (1966), *The Tacit Dimension*. University of Chicago Press, Chicago.

Popay J. (2005) Moving beyond floccinaucinihilipilification: enhancing the utility of systematic reviews. *Journal of Clinical Epidemiology* **58**(11), 1079-1080.

Pope C., Ziebland S. & Mays N. (2000) Qualitative research in healthcare. Analysing qualitative data. *BMJ* **320**(7227), 114-116.

Powell R.A., Single H.M. & Lloyd K.R. (1996) Focus groups in mental health research: Enhancing the validity of user and provider questionnaires. *International Journal of Social Psychiatry* **42**(3), 193-206.

Public Health Resources Unit (2006) *10 Questions to Help You Make Sense of Qualitative Research*. Public Health Resources Unit, Oxford.

Public Health Resources Unit (2013) *10 Questions to Help You Make Sense of a Randomised Control Trial*. Public Health Resources Unit, Oxford.

QRS (2011) *NVivo 9*. Melbourne: QRS International Pty Ltd. Retrieved from <http://www.qsrinternational.com/> on 25 May 2011.

RCN (2006) *Helping Students Get the Best from Their Practice Placements*. RCN, London Retrieved from [http://www.rcn.org.uk/data/assets/pdf\\_file/0011/78545/001815.pdf](http://www.rcn.org.uk/data/assets/pdf_file/0011/78545/001815.pdf) on 15 August 2014.

RCN (2007) *RCN Counselling Service*. Retrieved from <http://www.rcn.org.uk/support/services> on 10 June 2011.

RCN (2009) *Research Ethics: RCN Guidance for Nursing*. RCN, London.

RCN (2010) *Guidance on Safe Nurse Staffing Levels in the UK*. RCN, London.

Risjord M.W. (2011) *Nursing Knowledge: Science Practice and Philosophy*. Wiley-Blackwell, Chichester West Sussex.

Ritchie J., Lewis J., McNaughton Nicholls C. & Ormston R. (2014) *Qualitative Research Practice*. Sage, London.

Roberts D. (2008) Learning in clinical practice: the importance of peers. *Nursing Standard* **23**(12), 35-41.

Rodgers C. (1969) *Freedom to Learn*. Merrill, Ohio.

Ross M.M., McDonald B. & McGuinness J. (1996) The palliative care quiz for nursing (PCQN): the development of an instrument to measure nurses' knowledge of palliative care. *Journal of Advanced Nursing* **23**(2), 126-137.

Royal College of Emergency Medicine (2012) *End of Life Care in the Emergency Department: Best Practice Guidelines*. The Royal College of Emergency Medicine, London. Retrieved from <http://www.rcem.ac.uk/Shop-Floor/Clinical%20Guidelines/College%20Guidelines/> on 12 December 2013.

Royal College of Emergency Medicine (2015) *End of Life Care in the Emergency Department: Best Practice Guidelines*. The Royal College of Emergency Medicine, London. Retrieved from <http://www.rcem.ac.uk/Shop-Floor/Clinical%20Guidelines/College%20Guidelines/> on 12 April 2015.

Royal College of Physicians and Marie Curie Cancer Care (2014) *National Care of the Dying Audit of Hospitals, England*. Royal College of Physicians, London.

- Ryan G.W. & Bernard H.R. (2003) Techniques to identify themes *Field Methods* **15**(1), 85-109.
- Salomon G. & Perkins D.N. (1998) Individual and social aspects of learning. *Review of Research in Education* **23**(1), 1-24.
- Sandelowski M. (1993) Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advanced Nursing Science* **16**(2), 1-8.
- Sandelowski M. (2006) Meta-Jeopardy: The crisis of representation in qualitative metasynthesis. *Nursing Outlook* **54**(1),10-16.
- Sandelowski M. (2007) Words that should be seen but not written. *Research in Nursing and Health* **30**(2),129-130.
- Sandelowski M. & Barroso J. (2003) Classifying the findings in qualitative studies. *Qualitative Health Research* **13**(7), 905-923.
- Saunders C.M. & Clarke D (2006) *Cicely Saunders: Selected Writing 1958-2004*. Oxford University Press, Oxford.
- Schon D.A. (1983) *The Reflective Practitioner*. Basic Books, New York.
- Schon D.A. (1987) *Educating the Reflective Practitioner: Towards a New Design for Teaching and Learning in the Professions*. Jossey Bass, San Francisco.
- Schutz A. (1962) *Collected Papers, Volume 1*. Martinus Nijhoff, The Hague.
- Sharples K. & Moseley L.G. (2011) Learning to learn self-regulation in practice: A 2 cohort evaluation. *Nurse Education in Practice* **11**(3),345-350.
- Shaw R.L., Booth A., Sutton A.J., Miller T., Smith J.A., Young B., Jones D.R. & Dixon-Woods M. (2004) Finding qualitative research: An evaluation of search strategies. *BMC Medical Research Methodology* **4**(1), 1-5.
- Silverman D. (2007) *Qualitative Research* Sage, Los Angeles.
- Smedley A. (2007) The self-directed readiness of first year bachelor of nursing students. *Journal of Research in Nursing* **12**(4), 373-385.
- Smith P. (1992) *The Emotional Labour of Nursing*. Macmillan, Houndsmills.
- Smith P. (2012) *The Emotional Labour of Nursing Revisited*. Palgrave Macmillan, Basingstoke.
- Smith-Stoner M. (2009) Using high fidelity simulation to teach nursing students about end-of-life care. *Nurse Education Perspectives* **30**(2),115-120.
- Speck P. (2003) Working with dying people. In *The Unconscious at Work*. (Obholzer A, Roberts V.Z. eds.), Routledge, London, pp 94-100.
- Spencer L., Ritchie J., O'Connor W., Morrell G, Ormston R. (2014) Analysis in Practice In *Qualitative Research Practice* (Ritchie J., Lewis J., McNaughton Nicholls C. & Ormston R.eds.) Sage, London, pp 295-346.



- Spouse J. (1998) Learning to nurse through legitimate peripheral participation. *Nurse Education Today* **18**(5), 345-351.
- Spouse J. (2001a) Bridging theory and practice in the supervisory relationship: a sociocultural perspective. *Nurse Education in Practice* **33**(4), 512-522.
- Spouse J. (2001b) Workplace learning: pre-registration nursing students perspectives. *Nurse Education in Practice* **1**(4), 149-156.
- Spouse J. (2003) *Professional Learning in Nursing*. Blackwell, Oxford.
- Strauss A.L. & Corbin J.M. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Sage Publications, Thousand Oaks.
- Stevens P.E. (1996) Focus groups: collecting aggregate-level Data to understand community health phenomena *Public Health Nursing* **13**(3), 170-176.
- Stockhausen L.J. (2006) Metier Artistry: Revealing reflection-inaction in every day practice. *Nurse Education Today* **26**(1), 54-62.
- Streubert-Speziale H.J. & Carpenter D.R. (2010) *Qualitative Reserach in Nursing: Advancing the Humanistic Imperative* 5th edn. Lippincott Williams and Wilkins, New York.
- Stroebe M. & Schut H. (1999) The dual process model of coping with bereavement: rationale and description. *Death Studies* **23**(30), 197-224.
- Suliman W.A. & Halabi J. (2007) Critical thinking, self-esteem and state anxiety of nursing students. *Nurse Education Today* **27** (2), 162-168.
- Sykes N. (2013) The end of the Liverpool Care Pathway. *Lancet Oncology* **14**(10), 926-927.
- Tennant M. (2006) *Psychology and Adult Learning* 2<sup>nd</sup> ed Routledge London.
- Terry L.M. & Carroll J. (2008) Dealing with death: first encounters for first-year nursing students. *British Journal of Nursing* **17**(12), 760-765.
- Theodosius C (2008) *Emotional Labour in Health Care: The Unmanaged Heart of Nursing*. Routledge, London.
- Thomas J., Jack B.A. & Jinks A.M. (2012) Resilience to care: a systematic review and meta-synthesis of the qualitative literature concerning the experiences of student nurses in adult hospital setting in the UK. *Nurse Education Today* **32**(6), 657-664.
- Timmins F. & Kaliszer M. (2002) Aspects of nurse education programmes that frequently cause stress to nursing students a fact finding sample survey. *Nurse Education Today*. **22**(3), 203-211.
- Twigg R.D. & Lynn M.C. (2012) Teaching end-of-life care via a hybrid simulation approach. *Journal of Hospice & Palliative Nursing* **14**(5), 374-379.
- UKCC (1986) *Project 2000*. UKCC, London.

- Upton D.J. (1999) How can we achieve evidence-based practice if we have a theory-practice gap in nursing today? *Journal of Advanced Nursing* **29**(3), 549-555.
- Van Manen M. (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Althouse Press, Ontario.
- Vaughn S. Schumm J.S. Sinagub J. (1996) *Focus Group Interviews in Education and Psychology*. Sage, Thousand Oaks.
- Vygotsky L. & Luria A. (1930) Tool and symbol in child development. In *The Vygotsky Reader* (Vander Veer R. & Valsiner J. 1994 eds.), Blackwell, Oxford, pp 99-174.
- Wakefield A.B. (1999) Changes that occur in nursing when a patient is categorised as terminally ill. *International Journal of Palliative Nursing* **5**(4), 171-176.
- Wakefield A. (2000) Nurses' responses to death and dying a need for relentless self-care. *International Journal of Nursing* **6**(5), 245-251.
- Ward M.J. & Lindeman C.A. (1978) Questionnaire for understanding the dying person and his family by Winget. In *Instruments for Measuring Nursing Practice and Other Health Care Variables: Volume 1 and Volume 2*. Public Health Service, Arlington Va, pp 62-66.
- Weissman G.V. (2011) Evaluating associate degree nursing students' self-efficacy in communication skills and attitudes in caring for the dying patient. *Teaching and Learning in Nursing* **6**(1), 64-72.
- Welch J.L. (1985) Researching Marketing Problems and Opportunities with Focus Groups. *Industrial Marketing Management* **14**(4), 245-253.
- White C., Woodfield K., Ritchie J. & Ormston R. (2014) Writing up Qualitative Research In *Qualitative Research Practice* (Ritchie J., Lewis J., McNaughton Nicholls C. & Ormston R.eds), Sage, London, pp367-400.
- Wibeck V., Dahlgren M. A. & Öberg G (2007) Learning in focus groups: an analytical dimension for enhancing focus. *Qualitative Research* **7**(2), 249-267.
- Wilkes L., Beale B., Hall E., Rees E., Watts B. & Denne C.(1998) Community nurses' descriptions of stress when caring in the home. *International Journal of Palliative Nursing* **4**(1), 14-20.
- Wilkinson S. (1998) Focus groups in health research *Journal of Health Psychology* **3**(3), 329-348.
- Wilkinson S. & Kitzinger C. (2000) Thinking differently about thinking positive: a discursive approach to cancer patients talk. *Social Science and Medicine* **50**(7), 797-811.
- Wilson V. (1997) A useful qualitative method for educational research? *British Education Research Journal* **23**(2), 209-224.

Wood D.J., Bruner J. & Ross G. (1976) The role of tutoring in problem solving. *Journal of Child Psychology and Psychiatry* **17**(2), 89-100.

Wong P.T.P., Reker G.T. & Gesser G. (1994) Death attitude profile-revised: A multidimensional measure of attitudes toward death. In *Death Anxiety Handbook: Research, Instrumentation and Application*. (Neimeyer R.A. ed.), Taylor & Francis, Washington DC, pp121-148.

Zauderer C.R. & Ganzer A.C. (2011) Cinematic technology: The role of visual learning. *Nurse Educator* **36**(2), 76-79.

Zeller RA. (1993) Combining qualitative and quantitative techniques to develop culturally sensitive measures. In *Methodological Issues in AIDS Behavioural Research* (Ostrow DG & Kessler RC. eds.), Plenum, New York pp 95-116.

Zimmermann B.J. & Schunk D.H. (1989) *Self-Regulated Learning and Academic Achievement. Theory, Research and Practice*. Springer-Verlag, New York.

Zimmermann B.J. & Schunk D.H. (2011) *Handbook of Self-Regulation of Learning and Performance*. Routledge Taylor & Francis Group, New York.

## Appendix 1 Comparison of domains for education in end-of-life-care

Key and References:

CCC= Common Core Competencies in EOLC (DH 2009);

Domains for Education in Palliative Care (De Vlieger 2004b);

ESC= Essential Skills Cluster for Pre-Registration Nurses (NMC 2004);

P-RNs=Pre-Registration Nurses;

Standards= Standards of Proficiency for Pre-registration Nursing Education (NMC 2007)

Domains for education in palliative care (De Vlieger 2004b)	Level A	Level B	Level C	Standards (NMC 2007)	ESC (NMC 2004)	CCC (DH 2009)
	Basic P-RNs	Advanced	Specialist			
<b>1. The Patient</b>						
<u>Evaluation: Assessment tools, differential diagnosis</u>		X	X	A,B,F,H,I,J,K,O	1,2,5,7,9,10	2
Common symptoms: pain; dyspnoea; anorexia; confusion	X		X	B,D,E,F,G,H,I,K,O	1,2,5,7,9,10,19,27,28,29,30,31,32	2
Applied pharmacology: treatment; side-effects		X	X		1,3,34,35,36,37,38,39,40,41,42	3
Drug pharmacokinetics and drug interactions	X	X	X			3
Route of administration			X	O	1,20,33,34,35,36,37,38,39,40,41,42	3
Emergencies: e.g. spinal cord compression		X	X			2,3
Difficult symptoms e.g. fungating wounds		X	X		21,22,23,24,25,26	2,3
Psychological and/or psychiatric intervention		X	X			2,3
Role of the physiotherapist and occupational therapist		X	X			
Spiritual approaches to care		X	X			
Comfort measures: mouth care; bathing; pressure area care	X	X	X	A,B,D,E,F,G,H,I,J,K,O	1,2,3,5,6,17,21,22,23,24,25,26	2,3
Total pain	X	X	X	K	1,2,3,5,7,10	2,3
Pain assessment	X	X	X	K	1,2,10	2,3
Pain management: WHO analgesic ladder	X	X	X	B,F,G,H,I,J,K,O	1,2,19,20,33,34,35,36,37,38,39,40,41,42	2,3
Opiate options; titration; toxicity		X	X	K,O	1,33,34,35,36,37,38,39,40,41,42	2,3
Opiate rotation		X	X			2,3
Indications for choosing different opioids		X	X			2,3
Patient education on the use of opioids	X	X	X	D,F,G,H,I,J,K	1,3,6	1
Specifically situations: elderly and paediatric		X	X			2,3
<u>Terminal phase and death</u>		X	X		1	2,4
Anticipation of the terminal phase of life	X	X	X	D,F,G,H,I,J,K	1,3,7	2,3
Manage end-of-life symptoms	X	X	X	D,K	1,3,7,9,10,16,17	2,3
Issues of sedation at end-of-life		X	X			2,3
Supportive care of the dying person and family	X	X	X	C,D,F,G,H,I,J,K	2,3,5,6,12	1,2,3
Spiritual support		X	X			1,2,3

Domains for education in palliative care (De Vlieger 2004b)	Level A	Level B	Level C	Standards (NMC 2007)	ESC (NMC 2004)	CCC (DH 2009)
	Basic P-RNs	Advanced	Specialist			
<b>2. The patient and family</b>						
Impact of serious illness on the family: body image; sexuality; psychological; spiritual suffering and modification	X	X	X	C,D,F,G,H,I,J,K	2,3,5	1,5
Social consequences of serious illness: work; finances; support mechanisms	X	X	X	D,E	2,5,6	1,5
Breaking bad news, and dealing with differing emotional responses	X	X	X	A,B,D	3,5,6,12	1,5
Knowledge of systematic approach	X	X	X	D	1,6	4,5
Education of patient, family and carers	X	X	X	B,D,E	2,4,6	1,4,5
Family meeting/case conference		X	X			1,4,5
Supporting complex situations through negotiation to prevent conflict		X	X		17,18,19	1,4,5
Terminal phase; death; bereavement; process of grief and loss	X	X	X	B,D,F,G,H,I,J	1,3,4,5	1,4,5
Specific care of the grieving child			X			1,4,5
Religious rites and customs		X	X	C	1,3,4	1,4,5
Developing systems that individual or group brief in support			X			1,4,5
<b>3. Interdisciplinary</b>		X				
Roles and responsibilities of different team members, including volunteers and families	X	X	X	C,K,M,N	1,13,14,16,17	5
Group dynamics at leadership		X	X			5
The influence of patient and family on the team dynamic		X	X			5
Negotiation during team conflict		X	X	M,N	14,15,19	5
Networking and methods of working with other specialist team			X			5
Advice and consultation by team members	X		X		1	5
Methods to introduce change into the team		X	X			5
<b>4. Self-awareness ethical issues</b>		X				
Reflections on personal journey: values relating to live, end of life and death	X	X	X	A,B,K	1	5

Domains for education in palliative care (De Vlieger 2004b)	Level A	Level B	Level C	Standards (NMC 2007)	ESC (NMC 2004)	CCC (DH 2009)
	Basic P-RNs	Advanced	Specialist			
Coping mechanisms: projection; transfer; counter transference; personal limitations; burnout; caring for carers		X	X	A,K	1	5
The limitations of medicine and caring	X	X	X	A,K,M	1,14,15	5
Ethics: respect; patient's rights; dignity; autonomy; beneficence; non-maleficence	X	X	X	A,B,C	1,3,4,11	
Ethical decision-making; informed consent; judgement; patient wishes; advanced directives	X	X	X	A,B,C	1,3,4,5	
Global understanding of the request for euthanasia	X	X	X	A,C	1,3,4,	
Requests for euthanasia and possible responses		X	X	A		
<b>5. Death in society: palliative care in the healthcare system</b>						
Definition of medicine and palliative care and its implications the clinical practice and core values	X	X	X	K,P,Q	1,16,17	5
Epidemiology of the non-curable illness	X	X	X	K,P,Q	1	5
Quality-of-life model of bio-psycho-social care	X	X	X	E,K,P,Q	1,2,3,4,5	5
Death and dying; the medicalisation of death; taboos surrounding death	X	X	X	C,K,P,Q	1,2,3,4,5,14	5
Informed consent	X	X	X	B	1,3,6,7,8	5
Culture and spiritual aspects of illness, death and grief	X	X	X	C	4,6	5
Legal aspects of end-of-life care			X			5
How the institution works, management structures		X	X			5
Factors which influence resistance to change within institutions		X	X			5
Organisation of palliative care at the local; national; international level			X			5
Structure and models of palliative services	X	X	X	K,P,Q		5
The role of local; national and international palliative care organisations		X	X		1,11,16,17	5
<b>6. Training for educators and palliative care</b>						
Education			X			
Natural and international education in palliative care			X			
Knowledge of existing education system in the country		X	X			

Domains for education in palliative care (De Vlieger 2004b)	Level A	Level B	Level C	Standards (NMC 2007)	ESC (NMC 2004)	CCC (DH 2009)
	Basic P-RNs	Advanced	Specialist			
Evaluation of education programme			X			
Evaluation of clinical practice			X			
Understand the concept research-based practice			X			
<b>7. Training in palliative care research</b>						
Critical reading an academic writing skill		X	X			
Understanding research. Developing research tools			X			
Methods of data collection and analysis			X			
Multidisciplinary research			X			

## Appendix 2 Outcome measurement tools validity and reliability

Name/year/tool/(studies)	Validity test	Reliability test
<b>Attitude Outcome Measures</b>		
Bradley (2005) Attitude About Care at the End of Life 12 questions devised for qualified nurses, doctors (Kwekkeboom et al 2005, 2006)	Devised from 1. Medical nursing literature 2. Interview 8 nurses, 4 doctors 3. Pilot 10 nurses/doctors. 4. Construct validity	Test retest. Internal consistency Cronbach alpha 0.60 Modified: Low reliability Cronbach (alpha <0.38) (Kwekkeboom et al 2006)
Collett-Lester (1969) Collett-Lester Fear of Death Scale 36 items death anxiety fear of death in self and others. Six point scale (Degner & Gow 1988).	Not discussed by authors	Test retest at 7 weeks Pilot with 99 nursing students. Three sequential testing 0.80, 0.84, 0.83. Subscale unacceptably low 0.31-0.75 so total scale score used (Degner & Gow 1988)
Frommelt (1991) Frommelt Attitude Towards Care of the Dying (FATCOD) Demographic and 30 items Likert type scale. (Mallory 2003, Barrere et al 2008, Dobbins 2011, Weissman 2011)	Content validity index computed at 1.00 Inter-rater agreement of 0.98	Test retest: 18 oncology nurses Pearson Coefficient score r=94 30 oncology and surgical nurses Pearson Coefficient score r=0.90 Cronbach alpha: Pre-test .87 post-test .82. (Weissman 2011)
Milton (1984) Concerns about Caring for Dying Patients. Emotional support to grieving families, patients and self. Likert type scale. (Kwekkeboom et al 2005, 2006)	Not discussed	Not discussed
Mazor et al (2004) Concerns about Dying 10 descriptive statements (Twigg & Lynn 2012)	Compared scores with DAP-R (Wong et al 1994)	Adequate reliability. Total 207 Medical =62 Nursing students =47 Hospice nurses =50 Non-healthcare = 48 Test-retest three weeks Cronbach alpha combined .89 (Mazor et al 2004)
Winget Questionnaire for Understanding the Dying Person and his Family (Ward and Lindeman 1978) 50 item Likert type scale (Degner & Gow 1988)	134 nursing students Discriminate validity (t=8.69 for mean scores, p<0.001) Construct validity assessed	Coefficient alpha was 0.72 (Winget 1978) Pilot with 99 students, adequate Cronbach alpha =0.82 (Degner & Gow 1988)
Wong et al (1994) Death Anxiety Profile Revised (DAP-R) 32 item measurement of attitudes towards fear of death. Seven point scale (Dobbins 2011)	Tested on 300 general public 100 aged 18-29 years 100 aged 30-59 years 100 aged 60-90 years Predicted correlations confirmed attest to the construct validity	Test retest coefficients of stability good to very good reliability Cronbach alpha coefficients internal consistency low.65 to high .97 Stability coefficients: low.61 to high of.95 (Wong et al 1994)
<b>Knowledge Outcome Measures</b>		
Fluharty et al (2012) Knowledge Related to End-of-Life Care. 10 questions about symptoms and comfort interventions. Score 0-10	Content validity by 12 expert reviewers.	Not discussed
Moreland et al (2012) Knowledge Assessment Instrument Seven items recognise signs of death	Face validity by three doctoral nurses	Not discussed
Ross et al (1996) Palliative Care Questionnaire for Nurses PCQN 20 questions (Arber 2001, Kwekkeboom et al 2005, 2006)	Face validity experts review	Test retest reliability Correlation coefficient was 0.56 No statistically significant or meaningful differences (t=0.19,d.f=27,P=0.99) (Ross et al 1996)



<b>Name/year/tool/(studies)</b>	<b>Validity test</b>	<b>Reliability test</b>
<b>Knowledge Outcome Measures</b>		
Twigg & Lynn (2012) Knowledge in End-of-Life Care. Eight multiple choice items	Established testing validity	Not discussed Pilot study Baccalaureate nurses=16 (Twigg & Lynn 2012)
<b>Behaviour Outcome Measures</b>		
Fluharty (2012) Self-confidence in Caring for a Dying Patient and in Nursing. 30 items Likert-type scale	Face validity	329 nursing students Baccalaureate =37 Associate degree =81 Accelerated baccalaureate 37 Cronbach alpha .95 (Fluharty 2012)
Fluharty (2012) End-of-Life Communication Assessment tool Four items Likert-type scale	Content validity established by 12 expert reviewers	329 nursing students Baccalaureate =37 Associate degree =81 Accelerated baccalaureate 37 Cronbach alpha .7 (Fluharty 2012)
Fluharty (2012) Satisfaction with the Instructional Method. Five items. Likert-type scale	Face validity	329 nursing students Baccalaureate =37 Associate degree =81 Accelerated baccalaureate 37 (Cronbach's alpha .95 Fluharty 2012)
Moreland et al (2012) Self-Efficacy Assessment Instrument, Eight items. Likert-type scale	Face validity three members of the faculty	14 Baccalaureate nursing students Female= 13, Male=1 Cronbach alpha .77 (Moreland et al 2012)
Weissman (2011) VAS Self efficacy Communication with a Dying patient. 100mm scale	Face validity	Not discussed

## Appendix 3 Permission from Head of Faculty

From: 

Sent: 05 July 2011 11:14

To: Hawkins, Sian;

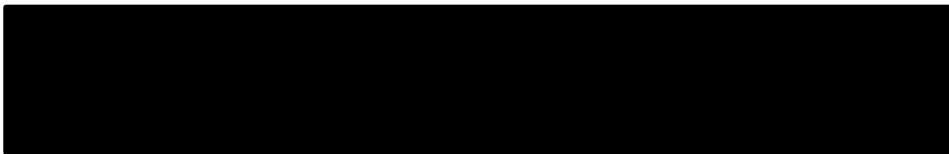
Subject: RE: Doctorate in Health Care

Dear Sian,

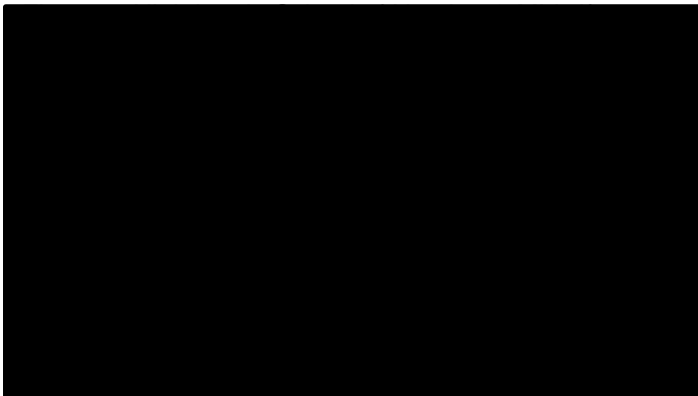
I have discussed your proposal with Dr Jo Armes and am prepared to sign off in this instance since I understand that the Ethics Committee have approved proposals where staff interview students within the College.

Do let me know the outcome of your search.

Best wishes,

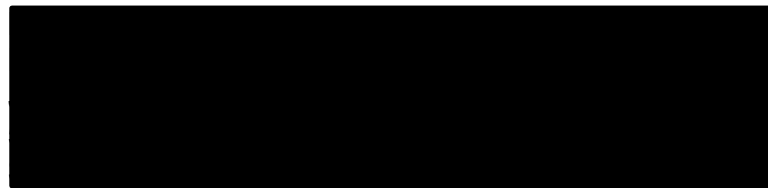


Head of School



## Appendix 4 Ethical approval letter

To: Sian Hawkins




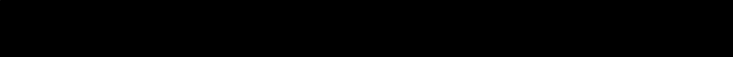
07 September 2011

Dear Sian,

### **PNM/10/11-150 How undergraduate pre-registration nurses learn to care for people who are dying**

Thank you for sending in the amendments requested to the above project. I am pleased to inform you that these meet the requirements of the PNM RESC and therefore that full approval is now granted.

Please ensure that you follow all relevant guidance as laid out in the   
Guidelines on Good Practice in Academic Research



For your information ethical approval is granted until 07 September 2014. If you need approval beyond this point you will need to apply for an extension to approval at least two weeks prior to this explaining why the extension is needed, (please note however that a full re-application will not be necessary unless the protocol has changed). You should also note that if your approval is for one year, you will not be sent a reminder when it is due to lapse.

If you do not start the project within three months of this letter please contact the Research Ethics Office. Should you need to modify the project or request an extension to approval you will need approval for this and should follow the guidance relating to modifying approved applications:



Any unforeseen ethical problems arising during the course of the project should be reported to the approving committee/panel. In the event of an untoward event or an adverse reaction a full report must be made to the Chairman of the approving committee/review panel within one week of the incident.

Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

If you have any query about any aspect of this ethical approval, please contact your panel/committee administrator in the first instance



We wish you every success with this work.

Yours sincerely,

James Patterson – Senior Research Ethics Officer

## Appendix 5 Recruitment email

### Recruitment email

**Title of Study: How undergraduate pre-registration nurses learn to care for people who are dying.**

Circular email for use for recruitment of volunteers for study [REDACTED]

**Research Ethics Committee Ref: PNM/10/11-150.**

This study has been approved by The Psychiatry, Nursing & Midwifery Research Ethics [REDACTED]. This project contributes to the College's role in conducting research, and teaching research methods. You are under no obligation to reply to this email, however if you choose to, participation in this research is voluntary and you may withdraw at any time.

I would like to invite you to take part in a study to explore undergraduate pre-registration nurses' perceptions of the education and support they receive to care for people who are dying. If you agree to take part you will be asked to sign a consent form, complete a Background Questionnaire and attend one focus group discussion that will last approximately one and a half hours. Please read the Participants Information Sheet attached which may answer your questions. If you are interested in participating please contact Sian Hawkins via [REDACTED] for further information. Please note that contacting me does not mean you have to take part in the study.

Thank you

## Appendix 6 Information sheet for participants

### INFORMATION SHEET FOR PARTICIPANTS

Research Ethics Committee Ref: PNM/10/11-150

**Title of Study: How undergraduate pre-registration nurses learn to care for people who are dying.**

#### Rationale for the study.

I am a lecturer at the [redacted] I am undertaking this research as part of a Doctorate in Health Care at [redacted]. I would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me (Sian Hawkins) if there is anything that is not clear or if you would like more information **about this study. My contact details are at the bottom of this information sheet.**

#### Study aims and benefits.

This study aims to explore undergraduate pre-registration student nurses perceptions of the education and support they receive to care for people who are dying. We are inviting undergraduate pre-registration students to discuss their views and experiences. This may not directly influence your education experiences, but may help other undergraduate pre-registration nursing students. You may enjoy the process of discussing and sharing within the group.

#### Who is being recruited?

Third year undergraduate pre-registration nurses will be invited to participate in the study as they have attended education about caring for people who are dying and may have experience of caring for dying adult patients during your placements.

#### What will happen if the participant agrees to take part?

If you agree to take part you will be sent a consent form to sign and given a copy to keep. A Background Questionnaire will be sent to you for completion. **The submission of the completed Background Questionnaire will be taken as consent to participate in the questionnaire element of this study.** I will then contact you with the date, time and venue of the focus group. The focus group is expected to last approximately one and half hours. There will be approximately 8 pre-registration students in the group. The [redacted] Maxwell Building on a date between October 2011 and February 2012. This will include refreshments. The focus group will explore your experiences of learning to care for adult patients who are dying. As the focus group proceeds a series of questions will be asked for discussion within the group. You may be asked an occasional question for clarification or to promote understanding, but mainly you will be listened to as you explain your experiences. The discussion will be audio tape recorded and transcribed. It will then be analysed in order to understand the focus groups experiences. You will be offered a copy of the final report to keep.

#### Any risks

During the focus group discussion we will discuss your experiences. While we do not anticipate that this will make you upset, it is possible that some of the discussion might raise strong

feeling/emotions. If this happens, the discussion will be stopped and you will be given the option to proceed or take a break to talk with another researcher. You can then decide to return to the focus group discussion or withdraw from the study. If you withdraw from the study your contribution to the interview will remain as it is part of the group discussion. At the end of the focus group there will be the opportunity for a group debrief with the researcher. There is also an option to discuss the situation through follow-up help numbers such as the RCN Counselling Service 0345 769 7064 and Kings College University Student Counselling service [http://www.kcl.ac.uk/about/structure/admin/facser/support/counselling/ counselling@kcl.ac.uk](http://www.kcl.ac.uk/about/structure/admin/facser/support/counselling/counselling@kcl.ac.uk)

The aim of this study is not to uncover instances of poor practice. Participants need to be aware that should criminal activities, including negligent practice or misconduct, be disclosed during the course of the focus group the researcher has a duty of care to report them to the relevant authorities according to the NMC (2008) Code and NMC (2010) Raising and Escalating Concerns.

#### **Arrangements for ensuring anonymity and confidentiality.**

- Each focus group will be audio taped and transcribed by the researcher. To ensure compliance with the Data Protection Act (1998), I will not use your name, or that of anyone mentioned including the names of wards or Trusts. The transcript will be labelled with an ID number instead of your name. A pseudonym will be used in written scripts. Recordings of interviews will be deleted upon transcription. The transcripts will be kept for four years in c [REDACTED] College London Ethics Committee policy (2009).
- **The personal information drawn from the Background Questionnaire and focus group will only be accessed by the Researcher (Sian Hawkins) and Research Supervisors (Dr Jo Armes and Dr Jaqualyn Moore). The [REDACTED] School of Nursing and Midwifery Kings College London will not have access to personal information.**
- As part of the dissertation I will utilise the material from your focus group for publications, teaching and conferences.
- If I want to use any material in any way not consistent with what is stated above, I will ask for your additional written consent.

#### **Withdrawing from the study**

- You can withdraw yourself from the study before or during the focus group. Withdrawing from the study will not affect your educational outcome. You cannot withdraw your data as it is part of a discussion.

#### **Written Consent**

If you do decide to take part you will be given this information sheet to keep and be sent a consent form to sign.

#### **Name and contact details of the researcher**

**Researcher Sian Hawkins contacted by email [REDACTED] Telephone [REDACTED]**

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### **If this study has harmed you in any way**

If this study has harmed you in any way you can contact King's College London using the details below for further advice and information:

**Supervisor [REDACTED] contacted by email [REDACTED] Telephone [REDACTED]**

## Appendix 7 Consent form

### CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

**Title of Study: How undergraduate pre-registration nurses learn to care for people who are dying.**

Research Ethics Committee Ref: PNM/10/11-150

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please  
tick or  
initial

- I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. I understand the data will remain in the study as it is part of the discussion.
- I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the Data Protection Act 1998.
- The information you have submitted will be published as a thesis and you will be sent a copy of the report. Please note that confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.
- I consent to the audio-recording of my contributions during the focus group discussion.

**Participant's Statement:**

I \_\_\_\_\_

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed

Date

**Investigator's Statement:**

I Sian Hawkins \_\_\_\_\_

Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signed Date \_\_\_\_\_

## Appendix 8 Background questionnaire

Research Ethics Committee Ref: PNM/10/11-150

**Title of Study: How undergraduate pre-registration nurses learn to care for people who are dying.**

### Background Questionnaire

Thank you for completing this brief questionnaire. It should take 5 minutes to complete. **This data will be anonymised.** Please tick the relevant boxes and include the details. Please return this to [sian.hawkins@kcl.ac.uk](mailto:sian.hawkins@kcl.ac.uk)

#### 1. Age in Years: Please tick

18-21  22-25  26-30  31-36  37-40  41-46  47-50  51-55   
 56-60

2. Gender: Male  Female

3. Experiences of caring for people who were dying before starting the BSc Nursing with Registration (Adult) Programme.

3.1. Health Care Assistant: YES  NO

If yes please identify the type of setting

---

3.2. Experience of caring for a family member or friend who was dying:

YES  NO

If yes please identify your relationship with the individual:

Grandparent  Parent  Sibling  Friend

Other \_\_\_\_\_

Please turn over to complete the questionnaire



#### 4. Nursing experience during the BSc Nursing Studies Programme.

Please tick the relevant placement areas if you cared for dying people during the placement.

Placement	Medical Ward	Surgical Ward	Primary Care	ITU	Accident and Emergency	Cancer Ward/Unit	Hospice	Other Please name
<b>1<sup>st</sup> year</b>								
1								
2								
<b>2<sup>nd</sup> year</b>								
1								
2								
3								
4								
<b>3<sup>rd</sup> year</b>								
1								

## Appendix 9 Topic guide

The focus group discussion was guided by the participant's contributions; however, the discussion was stimulated through the following questions.

TYPE OF QUESTION	EXAMPLE
Opening. The first question will be open-ended to facilitate the participants discussion	Please introduce yourself with your name and where you are working?
The concept of end-of-life care	<b>What does care of people who are dying mean to you?</b>
Preconceptions and expectations about caring for dying patients?	Before you started nursing what did you expect it would be like caring for dying people? What experiences of caring for dying people did you have before you started?
Knowledge	<b>What helps you learn to care for people who are dying?</b> How did you learn to care for dying people? Which educational experiences influenced the way you care for dying people? Can you give an example of a positive role model? Can you give an example of a situation where the experience with the role model was not positive? How do you think your knowledge to care for people who are dying has changed since you started your training? How can the educational experience be improved?
Caring for the dying and their family members	<b>Do you have any sessions on communication about breaking bad news?</b> <b>How do you learn to communicate with relatives and patients?</b> What aspects of your role when caring for dying patients do you find rewarding? Why was this rewarding? What aspects of your role was challenging? How did you feel about caring for dying patients? How do you feel about caring for family members?
Support	<b>Can you give me examples of what was supportive when caring for the dying?</b> What do you find supportive when you are in the clinical area? What do you not find supportive when you are in the clinical area? What do you do when you feel upset? How can support for pre-registration nurses be improved?

TYPE OF QUESTION	EXAMPLE
Explore care of people dying with non-cancer conditions, young people or post resuscitation.	How was caring for people without cancer different to people with cancer? What was it like caring for young people who were dying? What was it like when someone experienced a cardiac arrest? How could this experience be improved?
Whenever participants appear to generalise the researcher will insert a question that turns the discourse back.	Can you give an example? What was it like?
Bridging questions	We've been talking about... could we now move to..?
Possible questions to encourage conversation, clarify and probe the issues.	Could you explain that further? How do you mean? I think you're saying...? Do you mean...? Could you say more about...? What do other people think about...? What type of areas were you working in?
The researcher may return to participants to clarify any unclear issues and validate their responses.	What did you mean by.....? Could I ask you a few more questions about...?
Closing the session	Do you think there is anything that we have missed that we should talk about? Please reflect upon the discussion and identify which point is the most important to you? If this was an accurate summary?

## **Appendix 10 Reflection: Role of researcher/lecturer**

### **Reflection 20<sup>th</sup> October 2010 Role researcher/lecture (excerpt)**

My dual role of the researcher/lecturer, creates a hierarchy of power might inhibit recruitment and participants sharing their experiences. Participants may be concerned that their knowledge is being assessed. I needed to reduce this power relationship so I withdrew from teaching this cohort before they started in 2008. I explored different methodologies to reduce powers relationship while allowing to probe participant's answers...

Potential criticism of the organisation is a potential threat to the researcher/lecturer. I do not teach EOLC so will remain neutral about participant's opinions. Other lecturers may be defensive, therefore I discussed the research with the lecturers who taught EOLC and programme leads. They were enthusiastic as they wanted to promote P-RNs learning to improve patient care. As experienced lecturers we are used to receiving verbal and written evaluations and subsequently refining contents... So HEI and Trusts will receive positive findings and areas to develop...

## Appendix 11 Sample of open coding for FGA (excerpt)

Transcript FGA	Open Code
<p>A1. I remember the first patient I knew who died, it sounds a bit morbid. <u>I might have asked to see him as I have never seen a body and seen anything like that. I would not like to be a qualified nurse and not know how it was done.</u> So someone took me towards where the body was. She said, just feel him feel for his pulse. He did not have a pulse. Just to feel what it is like not to feel a pulse and look in his eyes, I think that <u>helped me a little bit as well in a strange way.</u> I don't know how to explain it. He <u>looked very peaceful after being in pain.</u> Recently in A&amp;E I had an experience of washing the body and that was quite good as well, though <u>I think it is hard, but it is a bit of closure as well.</u></p>	<p>Motivation to learn before qualified Self-regulated requested</p> <p>Nurse guided by talking through the process Helped learning Coping/understanding Patient peaceful helped to understand Emotional impact, helped manage emotions, closure</p>
<p>A2. I had an experience in A&amp;E where patient we were actually <u>discharging.</u> A lady arrested in the middle of the department. It was the first time I had done cardiac compressions. The entire time I was doing it <u>my mentor stopped what she was doing and she was standing by my side.</u> She talked me though it and was telling me it was <u>going to be ok and I was doing really well.</u> We lost the patient but about 45 minutes later the <u>consultant turned up and had brought everyone involved in the resuscitation coffees.</u> She said <u>let's just all stop what we are doing we have no patients in resuscitation. Let's sit down and talk and let's deal with this.</u> So we sat down and went through it. At the end she <u>said thank you.</u> It was nice. It was a <u>woman who was experienced and probably been qualified for over 30 years and yet she still needs to sit down and talk about it, and it was ok.</u> It was a really positive. I was fine <u>doing it again after that.</u> I think the team around you make a massive <u>difference to how you feel about the death afterwards.</u></p>	<p>Unexpected death New skills</p> <p>Mentor supported, encouraging coaching</p> <p>Team reflection Felt belonged to team Ok however experienced to explore this</p> <p>Valued by doctor Team Every one reflects and learns Felt could do it next time</p> <p>Team support very important Culture of debrief</p>
<p>A1. In A&amp;E.as well when we do resuscitation and someone says they are going to <u>stop and say the reasons why they are going to stop.</u> They go around <u>individually including students, they ask everyone around are you happy to stop. That is really nice as well, so you are acknowledged as part of the team and that you have a say in stopping. That is comforting to know you are working as a team.</u></p>	<p>Part of the team in A&amp;E Helped understand why stopped CPR Included in decision Comforting part of the team</p>
<p>A4. It is nice that they call upon students to help. There was an arrest in ITU and I had not seen one before. My <u>mentor said just go and watch, go and see it because it will be good for you.</u> I walked in and there were not many people there behind the curtains I was expecting everything to be under control. They shoved a clipboard into my hand and said <u>you are going to do the timing and writing. I was oh my gosh. I said I cannot do this because I have never done this before. They said 'that does not matter' you can write and you can look at a clock. It was nice that they acknowledge that you have not done it before but you need to do it and it would be really good for you to do it now.</u></p>	<p>Mentor found opportunity to learn</p> <p>Encouraged student to learn and be part of the CPR</p> <p>Felt valued as a learner Promoted learning Encouraged to learn Developed confidence</p>

## **Appendix 12 Reflection: Learning from personal bereavement**

**Date 7<sup>th</sup> September 2010 Learning from personal bereavement (excerpt)**

My most influential learning was by personal bereavement and family illness. My father died when I was 21 and my brother was 16 years old. Within the next ten years my mother experienced myocardial infarction, cancer, strokes, pulmonary emboli, several haemorrhages and finally died. It is difficult to give an exact account because it remains deeply private and sensitive. Despite this discomfort I have tried to provide a frank personal account of how these factors influenced my learning. I experienced the impact of hiding diagnosis from patients and relatives, feeling powerless when seeing unnecessary suffering, delirium and not being recognised by family members. In contrast there was the relief when nurses listened and improved my relatives' symptoms. Although this was one of the darkest periods of my life, these personal experiences shaped my nursing skills, behaviours and attitudes. These events gave me an insight into relatives and patients possible experiences and emotions. I incorporated helpful phrases used by the district and hospice nurses into my nursing practice. Through these experiences I learned how to approach and listen to relatives and patients. These interactions were cathartic and rewarding. This reflection made me question:

'Do previous personal experience of bereavement or being an HCA enhance and inhibit P-RN learning EOLC?'

