# A Mission of Privilege and Peril

## The Phenomenon of Community Palliative Nurses Caring for the Suffering

Beverley Mavin Pegg

Doctor of Philosophy

University of Technology, Sydney

2006

# Certificate

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text. I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Production Note:
Signature removed prior to publication.

# Acknowledgement

I am grateful for the generosity of many for their help, advice and support during the conduct and completion of this study. I thank:

- My partners in the endeavour, the nurses who gave of their time and their stories, showing to me generosity and graciousness in sharing their thoughts and feelings about caring for people who were suffering.
- My supervisors, Dr Michael Walsh and Dr Ann Adams for their ongoing support, encouragement and counsel that was more than one could hope.
- The Faculty of Nursing and Midwifery for their assistance and encouragement.
- The University of Technology for their understanding and assistance.
- My much loved cousin, Lynette, who encouraged me until she and her family took the journey of clients described by the nurses in the study.

An editor was engaged during the final draft stage of the thesis. The editor advised on document layout; technical matters of word processing; spelling, punctuation and grammar; conformity with the American Psychological Association Publication Manual; economy and consistency of expression; and minor, nonacademic issues about document organisation. All editorial comments were presented only as suggestions to the author, who exercised full discretion over every proposed change. The editor has a PhD in psychology and specialises in quantitative methods of social research; has no nursing qualifications or experience in community nursing or palliative care; nor significant involvement in phenomenological inquiry.

# Table of Contents

*page*

**Chapter 1 – Introduction ..... 12**

1.1 Background to the study ..... 12
1.1.1 Choosing the topic ..... 12
1.1.2 Nurses and suffering ..... 13
1.1.3 The purpose of the study. ..... 15
1.1.4 Structure of the thesis. ..... 15

**Chapter 2 – The Literature on Suffering ..... 17**

2.1 What it means to care for people who suffer ..... 17
2.1.1 Traditional concepts of suffering ..... 17
2.1.2 Modern concepts of suffering – the quest for meaning ..... 18
2.2 Suffering as a concern in health care ..... 20
2.2.1 Medicine and suffering ..... 20
2.2.2 Nursing and suffering ..... 25
2.2.3 Pain and suffering ..... 27
2.3 Nursing's response to the suffering of patients ..... 28
2.3.1 Witnessing the suffering of others ..... 29
2.3.2 Emotional labour and nursing ..... 33
2.4 Barriers to discussion and research on suffering ..... 34
2.4.1 Structural barriers to medical and nursing research into suffering ..... 35
2.5 Conclusions from Chapter 2 ..... 38

**Chapter 3 – Methodology: A phenomenological approach ..... 39**

3.1 Phenomenology and nursing ..... 39
3.1.1 Nursing knowledge ..... 39
3.1.2 New paradigms for nursing research ..... 40
3.2 Phenomenology as method ..... 42
3.2.1 Hermeneutic phenomenology ..... 42
3.2.2 The evolution of the phenomenological movement ..... 43

3.3 Phenomenology as method for nursing research ..... 50
3.3.1 Contributions from phenomenology ..... 50
3.4 Conclusions from Chapter 3 ..... 51

**Chapter 4 – Method: Researching the Phenomenon of Caring for People Who Suffer ..... 52**

4.1 Introduction to researching the phenomenon ..... 52
4.1.1 Research question and study aims ..... 52
4.2 Design of study ..... 53
4.2.1 Preparatory phase ..... 53
4.2.2 Recruitment ..... 54
4.2.3 The context ..... 55
4.2.4 Consent and other ethical concerns ..... 56
4.3 Participants in the study ..... 57
4.3.1 The researcher ..... 57
4.3.2 The nurses ..... 59
4.4 Data collection ..... 70
4.4.1 The process ..... 70
4.4.2 The interviews ..... 70
4.4.3 Data management ..... 73
4.5 Evaluation of research ..... 73
4.6 Data analysis ..... 75
4.6.1 The themes ..... 76
4.6.2 Developing the themes ..... 77
4.6.3 Interpretive meaning of the themes ..... 77
4.7 Conclusion to Method ..... 78

**Chapter 5 – Making the Journey ..... 80**

5.1 Introduction to Making the Journey ..... 80
5.2 Falling into the role ..... 81
5.2.1 Directed into the role ..... 82
5.2.2 Falling by chance ..... 84
5.3 Grasping opportunity ..... 87
5.3.1 Getting to learn ..... 87

5.3.2 Finding a caring practice setting....90
5.4 Having a leaning for the field....91
5.4.1 Knowing how....91
5.4.2 Doing the natural thing....93
5.5 Repairing the past....95
5.5.1 Doing better....95
5.6 Leaving the field....98
5.6.1 Having enough....98
5.6.2 Rejecting change....101
5.6.3 Needing to be for family....103
5.7 Living with leaving....105
5.7.1 Preparing to go....105
5.7.2 Feeling free....107
5.7.3 Looking back with longing....110
5.7.4 Looking to the future....113
5.8 Summary and conclusions from Chapter 5....114
5.8.1 Ways of making the journey....114
5.8.2 Being a sojourner in another world....115

**Chapter 6 – Knowing Suffering....117**

6.1 Introduction to participants' perceptions of suffering....117
6.2 Explaining suffering....118
6.2.1 The nature of suffering....118
6.2.2 The purpose of suffering....124
6.3 Recognising suffering....128
6.3.1 Hearing the words....129
6.3.2 Seeing the suffering body....131
6.3.3 Exposed to the anger....133
6.4 Causes of suffering....136
6.4.1 Denying reality....137
6.4.2 Effects of treatment....140
6.4.3 Barring access to relief....141
6.4.4 Family conflicts....148
6.4.5 Losing precious things....152

6.5 Summary and conclusions from Chapter 6 ..... 156
6.5.1 Ways of knowing suffering ..... 156
6.5.2 Being initiated ..... 157

**Chapter 7 – Giving Nursing Care ..... 159**

7.1 Giving nursing care ..... 159
7.2 Bringing clinical skills and knowledge ..... 160
7.2.1 Assessing the client and carer ..... 160
7.2.2 Giving relief with medications ..... 163
7.2.3 Enabling the client to stay at home ..... 167
7.3 Giving power to client and carer ..... 171
7.3.1 Giving acceptance ..... 171
7.3.2 Giving control ..... 175
7.3.3 Giving support ..... 183
7.4 Giving access to the sentient self ..... 188
7.4.1 Giving time to listen ..... 188
7.4.2 Giving permission to express emotions ..... 191
7.4.3 Giving access after hours ..... 196
7.4.4 Giving emotionally ..... 199
7.5 Summary and conclusions from Chapter 7 ..... 207
7.5.1 Ways of giving care ..... 207
7.5.2 Being all that they could ..... 207

**Chapter 8 – Receiving In Return ..... 209**

8.1 Receiving ..... 209
8.2 Gifts given ..... 210
8.2.1 Feeling fulfilled ..... 210
8.2.2 Feeling rewarded ..... 211
8.2.3 Feeling appreciated ..... 215
8.2.4 Receiving wisdom ..... 221
8.3 Sustaining wounds ..... 225
8.3.1 Feeling sad ..... 226
8.3.2 Feeling alone ..... 230
8.3.3 Getting tired ..... 236

8.3.4 Feeling threatened ..... 239
8.3.5 Taking on the suffering ..... 242
8.3.6 Feeling helpless ..... 245
8.3.7 Reliving one's own past suffering ..... 248
8.3.8 Facing vulnerability ..... 250
8.3.9 Feeling angry ..... 252
8.4 Summary and conclusions from Chapter 8 ..... 257
8.4.1 Ways of receiving ..... 257
8.4.2 Being enhanced ..... 258

**Chapter 9 – Finding a Balance ..... 259**

9.1 Introduction to finding a balance ..... 259
9.2 Knowing oneself ..... 260
9.2.1 Seeing the need for help ..... 260
9.2.2 Listening to their body ..... 263
9.2.3 Recalling their own wounds ..... 265
9.3 Helping oneself ..... 267
9.3.1 Having time off ..... 267
9.3.2 Seeking professional help ..... 269
9.3.3 Looking after one self ..... 272
9.3.4 Finding outlets ..... 276
9.4 Marking boundaries ..... 279
9.4.1 Using the border ..... 279
9.4.2 Washing it away ..... 283
9.4.3 Keeping the family out ..... 285
9.4.4 Moving on ..... 286
9.5 Summary and conclusion from Chapter 9 ..... 288
9.5.1 Ways of finding a balance ..... 288
9.5.2 Being mindful ..... 289

**Chapter 10 – Being a Nurse Caring for Suffering People ..... 290**

10.1 Introduction ..... 290
10.1.1 Entering into the experience ..... 290
10.2 Being a sojourner ..... 292

10.2.1 Searching and finding ..... 292
10.2.2 Seeking redemption ..... 293
10.2.3 Taking on and relinquishing responsibility ..... 294
10.2.4 Having courage ..... 295
10.3 Being initiated into the world of suffering ..... 296
10.3.1 Finding meaning. ..... 296
10.3.2 Observing with care ..... 298
10.3.3 Demonstrating sensitivity ..... 298
10.4 Being all that they could ..... 299
10.4.1 Demonstrating competence ..... 300
10.4.2 Countering helplessness ..... 301
10.4.3 Taking risks ..... 303
10.5 Being enhanced ..... 304
10.5.1 Receiving acknowledgement ..... 305
10.5.2 Gaining wisdom ..... 306
10.5.3 Learning about love ..... 306
10.5.4 Overcoming adversity ..... 307
10.5.5 Facing mortality ..... 307
10.6 Being mindful ..... 308
10.6.1 Being Honest ..... 308
10.6.2 Knowing oneself ..... 309
10.6.3 Protecting self and family ..... 310
10.6.4 Practising thoughtfulness ..... 311
10.7 Summary and conclusion ..... 311

**Chapter 11 – Conclusion and Discussion ..... 312**

11.1 Introduction ..... 312
11.2 Analysis and meaning ..... 312
11.2.1 The description of the phenomenon through onsciousness ..... 312
11.2.2 The description of the phenomenon through interpretation ..... 313
11.2.3 The phenomenon as a mission of privilege and peril ..... 314
11.3 Discussion ..... 317
11.3.1 Issues for nursing practice ..... 317
11.3.2 Issues for management ..... 321
11.3.3 Issues for nursing education ..... 322

11.4 Conclusion..... 322

**Appendix – Consent Form.....325**

**Bibliography .....327**

# Abstract

The experience of 12 community palliative care nurses has been investigated in a phenomenological study. The study described the phenomenon of caring for people who were suffering. The phenomenological description of the community palliative care nurses' role uncovered the structures of meaning of what it is to care for people who suffer. Following a sequence of steps aimed at analysing, interpreting and reflecting on the nurses' description of caring for people who are suffering, it was judged that this experience could be described as an experience of privilege and peril.

Five themes were drawn from the nurses' descriptions of caring for people who suffered. These five themes refer to the nurses' experience of caring for people who suffer as: making the journey knowing suffering, giving care, receiving, and keeping a balance. The essences of the phenomena were revealed in further reflection as Being a sojourner, Being initiated into the world of suffering, Being all that they can, Being enhanced, and Being mindful. The final hermeneutic description of the nurses' experience of caring for people who suffered as a mission of privilege and peril is drawn from each layer of meaning.