NURSING AND BEING NURSED
FROM PATIENTS’ PERSPECTIVES:
AN ETHNOGRAPHIC STUDY

A Thesis Submitted by Janet Hall, BN, Hons.
in Total Fulfilment
of the Requirements for the
Degree of Doctor of Philosophy

School of Nursing
Deakin University
February 2000
ACKNOWLEDGMENTS

Creating this thesis has been a long and arduous journey that has taught me much about nursing and the meaning of being nursed for people who become patients, and about compassion. Now, I wish to gratefully acknowledge every contribution that has made the study and its completion a reality with a collective thankyou.

As this inquiry emanated from my participation as a nurse researcher in a broad study (Keyzer, Hall, Mahnken & Keyzer, 1995) I would like to acknowledge the contribution of that study in leading to this thesis. Partaking in this research and working with others enabled me to continue to learn about nursing research in a supportive environment and, for this beginning, I thank my colleagues, Julie Mahnken and Professor Dirk Keyzer.

There are a number of special acknowledgments of sincere gratitude:

• to Julie, Pat and Dirk, for their personal and professional critique, encouragement and support, especially during times of uncertainty and change throughout the entire research process, and to Professor Keyzer who became my initial supervisor.

• to my colleagues and friends. It has been insightful nurturing by thoughtful people that made the continuation of the research possible from the cathartic effect of positive friendships, attitudes and beliefs of others.

• to Professor Helen Cox who was my mentor and in addition, became my supervisor. Helen encouraged me to continue to shape the thesis in my way, whilst helping me see through issues and work through concepts that I struggled with. Helen taught me so much, generously sharing her knowledge and wisdom, and caring about my experience as a student.

• to my family who generously gave me personal space in our family life to undertake this research. In particular, thankyou to Pete, Sean, Jarrod and Dion for sharing the common value that all people matter as unique individuals as it was this shared passion and belief in humanity that gave me the will to continue.

This thesis is dedicated to those people who participated in the research process. Their positive participation granted me privileged access to their very private world, enabling the study to have authenticity grounded in reality.
TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION TO THE RESEARCH

Introduction to the Research ................................................................. 7
Situating Oneself as the Researcher ...................................................... 8
Background .......................................................................................... 8
Background Literature .......................................................................... 10
Why Anthropology? ............................................................................. 11
An Overview of the Process .................................................................. 12
Aims of the Research .......................................................................... 13
Language ............................................................................................ 14
Implicit Assumptions .......................................................................... 16
Organisation of the Thesis .................................................................. 16

CHAPTER TWO: SETTING THE CONTEXT

Background Rationale .......................................................................... 21
The insider’s experience ...................................................................... 21
The discursive nature of nursing practice ......................................... 22
Issues of control that shape practice ............................................... 23
How nurses adapt ............................................................................. 24
Implications for patients .................................................................. 25
Literature as Cultural Knowledge ..................................................... 26
Reviewing the literature ................................................................... 27
Dominant themes from the literature .............................................. 28
Contrasting perspectives in literature ............................................. 31
The consequence of being a patient ............................................... 31
Imagery and reality .......................................................................... 32
Nursing History as Cultural Knowledge ......................................... 32
Selective nursing history ................................................................. 32
The mother country and nursing ................................................... 33
The Australian story .......................................................................... 35
Lay nursing and free settlers ............................................................ 36
Australian settlement and trained nurses .................................... 37
District nursing this century ............................................................. 38
Reflection on the historical discourse .......................................... 38
Linking rurality, district nursing and history .................................. 40
Other Literature as Artefacts of Nursing ........................................... 40
Images of nurses and nursing .......................................................... 40
Fictional literature challenges the dominant imagery ................... 42
CHAPTER THREE:
SITUATING THE SELF AND THE UNDERPINNING
PHILOSOPHY OF THE RESEARCH

Situating the Self ................................................................. 44
  The autobiographical self ................................................. 45
  Reflecting on the injury ..................................................... 47
  Privileged access ............................................................. 48

My Personal Philosophical Values ........................................... 49
  The principle of human dignity ......................................... 49
  The principle of autonomy .............................................. 50
  The bearing of emotions on morality ............................... 50

Philosophy and the art of nursing ........................................ 51
Mundane life patterns ....................................................... 52

Self, Philosophy and Methodology .......................................... 53
  Hermeneutic philosophy ................................................. 54
  An historical perspective ............................................... 55

CHAPTER FOUR:
METHODOLOGY

Why this Methodology? ......................................................... 59
The Concept of Culture ....................................................... 61

Anthropology as Methodology ............................................. 63
  An Historical Overview: Bronislaw Malinowski (1884-1942) .... 64

Anthropology and Ethnographic Process ............................... 65
  The Ethnographic Process ................................................ 66
  The Ethnographic Research Cycle ..................................... 67
  Fieldwork ........................................................................ 68
  Participant Observation ................................................... 69

Ethnographic Terms and Ways of Knowing ......................... 71
  Insider and Outsider ..................................................... 71
  Emic and Etic ............................................................... 72
  Multiple forms of data, data techniques and flipsiding ....... 72
  Taken-for-grantedness ................................................... 73

Attributes of Ethnography .................................................... 74
  Naturalism ....................................................................... 74
  Reflexivity ....................................................................... 75
  Respect ........................................................................... 75
  Truth and authenticity .................................................... 76

An Overview: Ethnographic process as a framework of inquiry .... 77
CHAPTER FIVE:
BEING IN THE FIELD

Introducing the Study ................................................................. 81
The Broad Cultural Landscape ....................................................... 82
  Rurality and the research ......................................................... 82
  Rurality and health ................................................................ 83
  District nursing in rural towns ................................................. 83
Local demographics of the district nursing service ...................... 85
  The pathway of access .......................................................... 87
  Negotiating access .................................................................. 88
  Ethical access ........................................................................ 89
Accessing Participants ................................................................. 90
  Nursing and gatekeeping ....................................................... 91
  Nursing .................................................................................. 92
  Nurses ................................................................................... 92
  The patients .......................................................................... 93
Being in the Field ......................................................................... 94
Methodological Issues in the Field ................................................. 94
  Concern about covert research .............................................. 95
  Taken-for-granted knowing ................................................... 96
  Reciprocity .......................................................................... 96
  Fieldwork ............................................................................ 97
Methodological Reflections .......................................................... 100
  An ongoing process ............................................................. 100
  Reflecting on access ............................................................ 100
  Reflecting on being in the field .............................................. 101

CHAPTER SIX:
THE NURSING NARRATIVE

The Places Nurses Work ............................................................. 104
The Morning Shift Commences ................................................... 105
Access ....................................................................................... 106
Nurses’ Routines ....................................................................... 107
Basic Nursing Care ..................................................................... 108
  Anna’s story ........................................................................ 109
  Margaret’s story ................................................................ 110
  Jim’s story .......................................................................... 111
Challenging Environments .......................................................... 112
  Nursing in the private domain of homes ............................... 114
Shaping Practice ........................................................................ 115
  Checking on Maggie ........................................................... 116
Organisational Time .................................................................. 118
Nursing those who are Dying ....................................................... 120
The PM Shift, a Different Focus and Different Needs .................. 122
Vera’s Story .............................................................................. 122
The Dilemma of Distance ........................................................... 124
The Shape of Practice on the PM Shift ....................................... 125
The Nature of Practice and Imagery ......................................... 127
Summarising the Nursing Narration .......................................... 127
CHAPTER SEVEN:
PATIENTS’ VOICES

Tomorrow I am Going to Re-write The English Language ......................... 129
Introducing the Patients............................................................................... 130
The Experiences of Being a Patient ............................................................ 132
  The concept of being a patient ............................................................. 133
  Gratitude .............................................................................................. 134
  Losing individuality and normality ..................................................... 135
  Sometimes they listen .......................................................................... 138
  Compromised lives .............................................................................. 139
  Whose needs? ...................................................................................... 142
  “I myself chose silence” ...................................................................... 143
Attributes of the Experience of Being a Patient .......................................... 143
  Dependence ......................................................................................... 144
  Being a patient inevitably implies vulnerability .................................. 144
  “I will only say good things” ............................................................... 145
Factors that Shape the Nurse-Patient Relationship ..................................... 147
  Reciprocity........................................................................................... 147
  Ways of nursing ................................................................................... 148
  Being in the home ................................................................................ 150
  Being an Insider .......................................................................................... 152

CHAPTER EIGHT:
PATIENTS AND HEALTH CULTURE: TIME AND SPACE

The Norms of Health Culture and Public Images ....................................... 156
  Cultural images .................................................................................... 157
    The community .................................................................................. 158
    Patients ........................................................................................ 160
    The sick role .............................................................................. 161
    Nurses ........................................................................................ 161
Patterns of Common Understandings .......................................................... 162
  Time and space as attributes shaping health culture ............................ 163
  Personal places, spaces and nursing .................................................... 165
Private Spaces.............................................................................................. 166
  Dealing with invasive nursing interactions ........................................ 167
  What was private became routine, a non-thing .................................... 169
  The consequences of loss of privacy ................................................... 169
Deviation from Time ................................................................................... 170
  Chronicity and the sick role ............................................................... 171
  The cultural of chronicity ................................................................. 172
  The in-between .................................................................................... 174
  Labelled as chronic .............................................................................. 174
  Rehabilitation ..................................................................................... 176
Moving out of the Medical Paradigm ......................................................... 177
The Emic and Etic Perspectives ............................................................... 178
CHAPTER NINE:
THE CULTURAL NORMS SHAPING PATIENTS’ EXPERIENCES
Medical Cosmology and the Shaping of Health Culture ...................... 181
The evolution of medical cosmology .................................................. 181
1. Bedside medicine .................................................................. 182
2. Hospital medicine .................................................................. 182
3. Laboratory medicine ............................................................. 183
4. Health as a negative value ...................................................... 183
The consequences of change ............................................................... 184
Nursing and medicine: An historical perspective .............................. 185
The implications of medical dominance for nursing ...................... 186
The implications of medical dominance on society ...................... 188
The implications of medical dominance for patients ................... 189
Linking Doctors, Nurses and Patients ......................................................... 190
Being a patient and being redefined from the acute paradigm .......... 191
Being redefined .................................................................................... 193
Being nursed in the home ........................................................... 193
Being constructed by language ................................................. 194
Being constructed by needs ....................................................... 195
Patient’s experiences of labelling and redefinition ..................... 196
The cultural norm ................................................................................ 197
Patient and Professional Ambiguities .......................................................... 198
Holistic care and patients’ experiences ............................................. 199
Who defines needs? ............................................................................. 201
Social construction .............................................................................. 203
Social history .................................................................................. 203
Causal relationships ........................................................................ 203
Distance ...................................................................................... 204
Culturally legitimated needs...................................................... 205
Allocation of scarce resources ................................................... 206
Cultural Complexity .................................................................................... 206

CHAPTER TEN:
MAKING SENSE OF HEALTH CULTURE
The Findings ............................................................................................. 210
Reflecting on participants’ roles in health culture .............................. 211
The Pathway or Map Through Health Culture ...................................... 212
Level one, entering the health care system ........................................ 213
Level two, being moved on ............................................................. 214
Level two (a) - ‘a psych consult’ .................................................. 215
Level two (b) - for rehabilitation and normalisation ...................... 215
Level three, getting on with life & the wellness paradigm .............. 217
Summarising the pathway ................................................................. 218
What this means for patients ............................................................... 218
Nursing Reinforces Cultural Norms ............................................................ 219
Nursing knowledge .............................................................................. 220
Nurses partake in the social construction of patients ......................... 220
Nurses actively partake in moving patients on .................................. 220
Ways of Nursing and the Experience of Patients ............................... 221
Ways of nursing ................................................................................... 221
Body language and silence ................................................................. 222
The use and abuse of language .......................................................... 223
Finding some meaning for patients? .................................................... 224
Nursing from a position of power as the cultural norm ...................... 224
Returning to Theory and Respect for Persons ................................... 225
The Implications for Nursing and District Nursing ......................... 226
The Hermeneutic Circle of Knowledge Acquisition .......................... 228
Summary .............................................................................................. 229

REFERENCE LIST .................................................................................... 231
The research was commenced to understand why patients submissively accept compliance in the nursing relationship. To understand this phenomenon, an anthropological perspective about nursing was sought through ethnographic processes, utilising The Ethnographic Research Cycle and The Developmental Research Sequence as detailed by James Spradley (1980). Ethnographic methods of fieldwork and participant observation were undertaken over a three month period in a district nursing service in a rural area of Victoria, Australia.

There are three overarching aims. The first is to record information at risk of being lost, hence the ethnography is an archival record describing insiders’ perspectives of nursing practice. Description brings into view broad contextual issues that shape nursing practice, the daily routines and cultural norms of nursing, whilst also giving voice to patients’ experiences about being nursed. The early part of the thesis is descriptive of the mundanity of nursing practice and of being a patient as these interactions are of fundamental significance in giving meaning to people’s lives.

Secondly the inquiry seeks to capture the meaning patients attach to nursing. Further description continued to uncover perspectives of nursing that were layered to present an integrated whole that still acknowledges the integrity of individuals and structures that make up that whole. As the cultural picture gained detail, the expected norms of being a nurse and a patient became evident, revealing how culture gives shape to nursing and being nursed. Notions of time and space were found to be constructs of being a patient which shape the illness experience. They are not necessarily within a patient’s control, nonetheless, there is a norm and deviation from this norm has consequences for patients.

Thirdly, the ethnography conveys the expected behaviour for a person who becomes a patient, to make known the implicit meanings, norms of behaviour and unwritten rules that a patient needs to understand as they pass through various stages of the health care system.

In conclusion, the ethnography consistently reveals the underlying conflict between what nurses believe they do and the meaning attached to the experience of being nursed. For example, some nurses practice with patients’ values as central to
practice; others believe they care, yet observation and patient conversations suggest that they do not. The ethnography revealed that society expects nurses to elicit and reinforce compliance. Similarly, the power of culture shapes the experience of patients as the desire to be accepted, as a personal need, and as a means of having their nursing needs met, means that patients will invariably be passively compliant. The consequence is that nurses have a dominant power differential over patients, therefore, if nursing is to continue to describe practice as humanistic and caring, they ought to actively seek to be aware of patients’ values and be motivated to accept these as central to practice.
PROLOGUE

THE PERSONAL EXPERIENCE

It was a dismal Sunday morning in October as I practised as a clinical nurse in charge of a busy medical ward that accommodated patients who were categorised as having acute and chronic medical conditions, some surgical, alongside patients for palliative care and rehabilitation. Being in charge provided opportunities and authority to bring about a level of change and, importantly, this position enabled me to consistently teach by example.

In my work that morning, I assisted each nurse to lift or transfer patients where a second nurse was needed. As was my way, I listened to the patient and sought to do the lift safely whilst considering how they liked to be moved. This inevitably was about feeling safe and causing the least pain. I assisted, demonstrating and discussing with the primary nurse how and why the patient and I moved. The ward was extremely busy with both high acuity and rehabilitation needs and responsibilities to be met, and yet confined by physical design that made the use of any lifting aids impossible. Within ten minutes I was asked to assist with another [my fourth] heavy transfer. There were only two of us there and it took three to transfer Pat. She wanted to go to the toilet and refused the bedpan, angrily calling out with frustration...

“All I want is to go to the toilet!”

Pat was elderly, frustrated and sick of the indignity of being a patient waiting to go to the toilet till other people were ready! Her body was broken and each day it seemed her spirits were being torn away. A seventy year old lady with chronic ill health and now, superimposed on this and her regular hospital stays, an un-united, compound fracture of the tibia and fibula.
I knew it was a risk, but the nurse (Mandy) and I organised equipment for a path slide transfer. How could we refuse a patient’s request - to go to the toilet in privacy rather than on the pan in a four bed ward? I put my arms under Pat’s arms, locking them together around her chest so she felt secure. Mandy took her legs and on the count we kept Pat’s body in alignment, assisting her to slide across on the powdered slide board to the commode. Half way across she called out,

“[t]his is too scary,”

whilst throwing her body back to the bed. Mandy was quick, kept the alignment and got Pat’s legs back in the bed. I was only guiding and had my arms locked under hers and around the chest.

She had thrown herself back in the bed and my body was twisted and pulled across with her. I stood beside the bed, twisted from the waist, my upper body underneath the woman as my arms were still encompassing her chest. It had been a powerful movement as she threw herself back into the bed in sudden fear of falling. It’s amazing the strength fear can muster - but, there I was, the nurse with a passion for nursing and teaching by example, crying underneath a patient and unable to move. It was an unexplainable sense as if something gave way in my spine and excruciating pain seared through my body and upper limbs. Other nurses lifted the patient off as I cried, lost by now in indescribable pain.

The nurses gently managed the situation as the pain killers and the fatigue that follow a critical incident lulled my senses...
CHAPTER ONE

INTRODUCTION TO THE RESEARCH

This chapter, introducing this study, commences by placing myself as the nurse researcher within the context of the research. In particular, I acknowledge the position and philosophical underpinnings that predetermine why and how I addressed this study. This thesis evolved from my personal nursing experiences, alongside my situation as a researcher, writer and interpreter, focusing the study on patients’ perspectives of being nursed. The research question and the type of knowledge sought led to the methodology; a brief discussion ensues outlining the concerns that are the background to the research and introducing the use of anthropology through ethnographic processes. Finally, an overview of the framework of the research is outlined.

Introduction to the Research

This research has evolved from my personal experience as a nurse, a patient and a woman within a rural community enacting each role as life deemed appropriate. When injury limited me to the singular status of being a patient, I encountered the experience of being confined to implicit expectations of benevolence, paternalism and dependence. I became an insider as I experienced the world of being a patient as only participants can appreciate.

The experience of being a patient was vastly contrary to my expectations since being a nurse, practising in various settings over a fifteen year time span to the time of injury, had in no way prepared me for the situation in which I now found myself. The insider’s experience of being a patient brought to the fore many issues about nursing practice that I had been struggling with throughout my career. These were grounded in my discontent, yet acceptance, of many taken-for-granted and accepted ways of nursing practice that actually disregard a patient’s individuality and integrity. Reflection on my vocation exposes a reality where the patient, as the central focus of what nursing was about, had not necessarily been the reality I was expected to participate in.
This compelled me to confront my belief and dedication to humanistic nursing, the culture of nursing, and the health care system, reinforcing my concerns about a contradiction in nursing practice, between what I believed ought to be and what occurred in reality. However, the personal experience as a patient was the culminating factor that meant I could no longer tolerate the paradox of practice. I needed to understand why (and how) nursing seemed to imply compliance, and why patients, inclusive of myself, did not perceive they had any choice.

This inquiry, therefore, develops an anthropological perspective and an insider’s point of view about the culture of nursing. The inquiry seeks to understand the patterns of behaviour and roles of nurses and patients, specifically focusing on how culture gives meaning to, and thus shapes, the experience of being a patient. It is grounded in the contention that nurses and patients need to understand the reality in which they participate and that nurses ought to appreciate the experience of those who are the primary focus of care: the patients.

**Situating Oneself as the Researcher**

The prologue and introduction have located my personal experience, where injury moved me to the other side, to an insider, exposed to society’s construction of meaning about who I was and the expected norms of behaviour as a patient. As this study was initiated by this personal experience, an anthropological perspective was sought using ethnographic processes where as the researcher I am inherently part of the inquiry. In accord with this position, the study is written in the first person and references to participants are inclusive of myself. Likewise, my personal experiences, beliefs and position are made explicit as it is inevitable, but also an important link in the spiral of knowledge acquisition, that the notion of self implicates on the interpretation of the research.

As an ethnography, the study is representative of the researcher’s epistemology at this time and place. As a mode of inquiry that seeks understanding, an ethnography also arguably moves from the epistemological position to the ontological perspective of what it is possible to know.

**Background**

Whilst the personal dilemma of being converted to a patient was embedded with connotations of compliance, I did not assume that it was nursing alone that elicited specific behaviour from patients. It was necessary, though, to understand how and why nursing was part of the scheme. The background to the study therefore
considers the surrounding social, cultural and political circumstances that impact on
the nursing situation, where nursing is a subculture within the broad construction of
our health care system, that is also referred to as health culture.

From the cultural perspective, nurses provide acts of nursing to patients, who are
recipients of nursing. The way a nurse practices is the culmination of personal
qualities, beliefs, and socialisation; alongside expectations and norms of the
employing institution and the regulation of practice by governing bodies in society.
Nursing is also a discipline with a distinct body of nursing knowledge and the level
of knowledge is yet another element that has the potential to shape an individual’s
practice. At the same time, being a patient is a constructed way of being. People are
individuals who mediate their personal qualities, beliefs and socialisation with their
altered situation and experience of illness; alongside society’s expectations and
inferences. When the nurse and patient meet, this is an interpersonal interaction,
where the norms have already been given shape by the surrounding culture, assuming
that patients are passive recipients who seek nursing knowledge and assistance from
a belief that the nurse knows best.

My search for nursing knowledge began by looking at the relationship between
nursing and ethics (Hall, 1993), and later, description of community based nursing
practice (Keyzer, Hall, Mahnken & Keyzer, 1995) that highlighted the ambiguity of
concepts such as patient directed nursing, holistic care and nursing’s adoption of a
professional code of ethics. In addition, nursing scholars were revealing similar
disparities between theory and practice. If the essence of nursing is to be found in
the nurse-patient interaction, then surely ethics ought to be inherent with practice, yet
personal nursing experience and literature such as Johnstone (1989) and Salvage
(1992) demonstrate that nurses are frequently unwilling, or are constrained by
institutional restraints and even law (Evans, 1986; Johnstone, 1989) from acting
according to patient’s values. Even meeting a patient’s expressed wishes may subject
the nurse to personal risk to the extent of losing their practicing rights, as employing
institutions frequently have overriding policies (such as routine resuscitation policies
and discharge policies) and governments have overriding laws which shape practice
(such as euthanasia). Additionally, nurses are employees and their employers are
funded according to the number of patients seen; there is no fiscal value for the
amount of nursing provided and no correlation between funding and patients’ needs.
Nurses are not necessarily valued by colleagues, employers or the law for
collaborating with patients, and at worst, this may constitute a criminal offence.
Nursing is typified by rhetorical discourse and contradictions between espoused theory regarding what nursing ought to do and what occurs in practice. It is an unquestionable reality that, in seeking medical (nursing) assistance, people are subjected to the values held by the hierarchy of staff (by doctors, nurses and administrators) without question. Disconcertingly, many patients do not perceive they have a choice (even about what time they shower or how often they use their bowels). If they are actually asked what they want the answers invariably indicate acceptance; a wish to be obliging, easy to get on with, to fit in with the system.

This position, having been my experience throughout my nursing career and more recently as a patient, remains problematic for me. What nursing is expected to be and what patients want from nurses deserves clarity or nurses will continue to be socialised into eliciting compliance and shaping people into patients to fit the norms of our culture. As a nurse and a patient I believe that (many) nurses practice with moral passion, with a desire to meet patients’ expressed needs. I know that this is already captured in nursing theory based in humanism, but as an insider I became acutely aware that it is certainly not the cultural norm.

My experience as a patient exposed a vast difference in society’s construction of meaning about who I was and the expected norms of behaviour. I experienced a change in status and gained an insider’s perspective as I learnt that being a patient meant accepting each nurse’s ways, routines and expectations; being a patient meant being agreeable and compliant.

**Background Literature**

The research was undertaken at a time when the literature reviewed and personal professional experience revealed a lack of recognition about nursing and being nursed at the most fundamental level of daily practice. Literature revealed a scant acknowledgement about basic mundane issues of nursing, such as what nurses do, how they go about doing it, and patients’ perspectives on being nursed. Consequently we do not know patients’ perspectives of what their needs are, what being nursed means, nor how nursing interactions are constructed where one has needs and the other the resources. Literature does not address the fact that we live in a community that has personal, professional and cultural expectations on a person who is a nurse, as well as an expected role with norms of behaviour for people who need nursing. Quite simply the literature does not address nursing as an interaction that is given meaning and shaped by the norms of the culture in which we live.
Nursing theorists such as Benner (1984), Paterson and Zderad (1976), and Watson (1990), clearly link the act of nursing with a moral concept of caring for patients and respect for their person. Other literature by scholars such as Hudson and Richmond (1994), Lawler (1991) and Taylor (1994) also captures the essence of nursing as the provision of wholistic care unique to each patient, their needs, values and life styles, with nursing grounded in morality, referred to by Carper (1978) as the art, aesthetics and ethics of nursing.

In contrast however, other literature revealed nurses failing to appreciate the meaning of being nursed for patients, as exemplified by the categorisation and labelling of patients who do not conform to expected roles as deviant and bad (Draper, 1992, a & b; Rawlinson, 1999; Roach Anleu, 1991; Stockwell, 1984). As a result, patients are subject to benevolence, paternalism, labelling, and expectations of compliance, to norms of behaviour that are common patterns within our culture. The paucity within the literature has meant that the meanings and experiences of being nursed from patients’ perspectives remains unappreciated and unrecognised.

It is not the norm in ethnography to undertake a literature search (Spradley, 1980), however, literature was used in three particular ways. Initially, literature was explored as a prelude to set the context of the research, to acknowledge previous research, and to avoid only seeing the dominant to the detriment of silenced nuances and the taken-for-grantedness of practice. Secondly, literature was accessed during the writing of the ethnography to support or elicit further inquiry into cultural domains as multiple forms of data add to the sense of truth. Thirdly, literature reveals dominant cultural themes.

**Why Anthropology?**

It was imperative that the methodology was able to capture the uniqueness of nursing. As all research has the potential to impact on theory and practice, the methodology needed to be grounded within practice, in actual instances of persons who are experiencing the situation of being nurses and patients, to capture what has traditionally remained silenced (Cox, Hickson & Taylor, 1991; Meerabeau, 1991). This includes the nuances, tacit, taken-for-granted and silenced perspectives of nursing, as well as the meaning patients attach to the nursing experience. As the phenomenon of nursing is grounded in interactions that are a product of patients, nurses and the physical and contextual environment in which nursing occurs, anthropology provided a mode of inquiry that could reveal the type of information sought.
Anthropology focuses on learning from the participants (Spradley 1980), emphasising interactions between people and their environment (Hughes, 1991). As the study of human culture (Barrett, 1991) anthropology provided the means to look at what it means to be a patient. The methods are grounded within emic or the insider’s knowledge; a way of knowing that is uniquely important in areas where little research has been done before (Miller, 1991), or as Barrett (1991) notes, when the information is at risk of being lost. As qualitative research stemming from the interpretive paradigm, anthropology is underpinned by the hermeneutical circle or spiral of knowledge acquisition (Odman, 1988), valuing the significance of personal experience and knowledge.

My dilemma was that I was the researcher and an insider to both nursing and being a patient. I believed that (most) nurses practice from a moral belief to care and help others but I was also a patient who experienced a different social reality on the other side, where my way of life and personal integrity were compromised. The methods of anthropology appropriately value this prior knowing as a contribution to the cyclic nature of knowledge acquisition and as a unique awareness of the tacit and taken-for-granted ways within nursing culture. This was important because the inquiry was necessarily grounded in my prior knowledge, drawing on the autobiographical experience (as expounded on by Judith Okley, in Own or Other Culture, 1996) whilst expanding on this way of knowing through further inquiry in the field.

**An Overview of the Process**

The inquiry sought an anthropological perspective through ethnographic processes as detailed by James Spradley in Participant Observation (1980). Ethnographic processes enabled me, as the first person researcher, to review the culture I participated in as a nurse, a patient, and as a member of the broader community. The ethnography sought to gain an empathetic understanding of the insider’s perspective about the culture of nursing through ethnographic methods of fieldwork and participant observation to produce an ethnographic text. Throughout the text, exemplars are used to illustrate the findings. Each one is drawn from the various forms of fieldnotes specific to this ethnographic fieldwork, unless otherwise referenced.

Inquiry was undertaken through a rural district nursing service, as rural nursing was a particular area of interest due to the context of my own nursing career. District nursing in a rural context was also a unique research setting as nursing takes place in an environment that is less socially constructed and controlled than in hospitals.
Patients are seen in their own homes and nurses work by themselves in people’s homes, whilst frequently, the same nurse and patient interact over an extended length of time. The district nursing service was a discrete nursing unit attached to a ‘base’ hospital in a rural area of Victoria, Australia. The participants were the ten nurses who formed this nursing unit, along with twenty patients who were broadly representative of the demographics of the district nursing service such as age, gender, socio-economic status and the area in which they lived. The fieldwork was undertaken over a three month period with the nurses as gatekeepers to accessing patients in their homes.

The first phase is searching inquiry asking ‘what is this?’ by describing the salient obvious and mundane reality about what is occurring in the setting. The second phase asks ‘what is happening here?’ explaining, describing, and relation searching; whilst the third phase asks ‘but why is it happening?’ as analysis continues by searching for themes and their relation to the culture (Germain, 1986). No stage occurs in isolation. Analysis moves the insight gained from emic instances to etic generalisations; that is, from the particular to a general observation. Patterns of common thought or behaviour are then considered as a cultural norm. Simultaneously, generalisations must be supported by the subjective data and so the ethnographic product, that is a text about the culture, weaves its way back and forth between the general to the particular and back to the general.

The challenge was to discern, understand, appreciate and articulate nursing interactions as I believe that these are important in shaping the outcomes of nursing practice and the ongoing meaning patient’s attach to their lives.

**Aims of the Research**

The overall objective of the research was to understand why it is the cultural norm for patients to experience submissive expectations. Subsequently, the anthropological perspective aims to reveal three levels of cultural understanding which are then layered and analysed to enhance an understanding of the experience of being nursed and why patients are submissively compliant.

As a consequence, the underpinning aims of the inquiry are:

- to expose and record information which has remained silenced, or is at risk of becoming lost, by describing everyday mundane nursing practice from the multiple perspectives that occur within the construction of practice from the emic or insider’s reality;
• to uncover cultural knowledge such as the social and practical complexities of nursing practice, the covert influences that shape the experiences of people who become patients, and the meanings attached to nurse-patient interactions;
• to enhance understanding of the cultural issues that give meaning to and shape the experience of being a patient, such as the implicit meanings, norms of behaviour and unwritten rules that a patient needs to understand as they move through health culture.

Language

In introducing an ethnographic text the use of specific language requires further explanation: terms used throughout the text are dealt with now, whilst various stages of the inquiry utilise various forms of language which are defined and explored when used. As a general rule, however, the methodological principles of respect, collaboration, and reciprocity, reinforce the point that language is not the researcher’s prerogative as an ethnographic inquiry ought to be the participant’s version of reality. The language of the participants, referred to as ‘folk language’ (Spradley, 1980), is maintained throughout the data collection and is inherently part of the data. Folk words and phrases are identified by single quote marks on their initial use whilst subsequently they are naturally subsumed within the text.

During the fieldwork, it was noted that the patients used folk language or terms common to their situation, the most notable example being the use of the word ‘patient’. The nurses also used folk language, especially when they were in the community and patients’ homes, whilst they also used specific nursing language or jargon such as ‘doing a BSL’. In addition, there were common nursing terms such as ‘needs’, ‘deficits’, ‘care’, ‘health’, ‘illness’ and ‘disease’; as well as medical terminology that were used by both parties, to varying degrees, depending on the situation. For example, the common usage of medical terms persists throughout the thesis as nursing takes place within the medical paradigm, hence, these terms are part of the nursing discourse in formal environments, whilst the language of the nurses was less jargonistic in patients’ homes. Similarly, as patients became socialised into nursing they accumulated medical language and, over time, their narrations increasingly included medical terms along with lay and folk language.

Gender language is also maintained as it reflects reality. The nurses who consented to participate were all female registered nurses who were referred to as ‘RN’s’ or simply as the nurse or ‘she’ in conversations.
The word ‘rural’ describes the demographic nature of the research setting. The participants and local people whom I asked, all referred to the area as rural and therefore it is accepted as the local folk language that has particular meaning for the participants. The local context of the term rural, implies the area is relatively distant to metropolitan regions where businesses, governments and health services are centralised, and the essence of life in rural areas in Australia is commonly referred to as ‘rurality’.

The terms tacit, taken-for-grantedness, nuances and everyday knowledge are each used in this study with slightly differing connotations. Tacit for example, means that something is implied without being stated (Turner, 1987, p.1155), but the implication is that participants do not necessarily know why, it is simply accepted as the norm. Likewise, taken-for-granted knowledge and ways of practice are accepted norms but these ways are so common and accepted that nurses and patients often do not realise what is occurring, therefore they remain unquestioned and even unrecognised (Lawler, 1991). Further to this, everyday knowledge is common and taken-for-granted but it is clear what is occurring. Silenced knowledge and practices are those subconsciously removed from public view; the consequence is that this knowledge and these actions will remain silenced, not public knowledge and therefore never valued, funded or legitimised. Nuances are subtle differences and, again, nuances in nursing are ways that hide or make less public what is occurring. The consequence of nuances is similar to silencing as there will be no recognition or value.

Specific ethnographic terms such as insider, outsider and sanction that are integral to the text and ingrained throughout the thesis are also explained. An insider is an intimate participant in that culture. An outsider is a person such as the reader who looks in. They are not an intimate participant and rarely are they able to impute the same meaning to an interaction. Ethnography seeks the insider’s point of view, accepting every perspective as a person’s subjective reality.

Sanctions are formal and informal mechanisms that society uses to achieve social control and conformity to what are regarded as proper behaviour or social norms (Freedman, Hawley, Landecker, Lenski & Miner, 1956, p.123; Roach Anleu, 1991, p.5; Turner, 1987, p.985). They may be rewards for conformity to social norms or punishments for norm violations, as social control prescribes certain actions and proscribes others. To sanction a behaviour is to ratify it as acceptable or deviant by formal or informal mechanisms. Formal controls are the legal system, whilst society also utilises less overt informal social control, where social groups (such as the
medical profession) make rules and enforce their definitions on society through judgements such as pronouncements of approval or dismissing a person’s symptoms, thereby putting down or oppressing subjective experiences. Informal social sanctions even include “… ridicule, praise, gossip, smiles and glances to ostracism” (Roach Anleu, 1991, p.5).

Likewise, Bradshaw’s taxonomy of needs is also used throughout the thesis. It is acknowledged that any taxonomy is a biased system for describing needs, therefore, where possible, needs are best understood and transmitted through patients’ language and stories, however, to move the concept of needs to a generalist level, it is helpful to have formalised terminology. The following provides a brief overview of descriptors and meanings from Bradshaw’s taxonomy (1972):

• normative need - those accepted and laid down by the profession;
• felt need - patient wants;
• expressed need - felt need (wants) converted into action;
• comparative need - similar needs within a given population.

**Implicit Assumptions**

The assumptions which underpin this inquiry are simply

• that the experience of being nursed matters and gives meaning to people’s illness experience;
• that nursing ought to emanate from patients’ needs;
• conversely, that patients’ values ought to be central to nursing practice and
• that nursing does make a difference and is potentially therapeutic in its self.

**Organisation of the Thesis**

The thesis is organised into ten chapters. The initial chapters provide an overview of the research and set the context for an ethnography. Chapter four details the methodology and an outline of the proposed research process. Being in the Field begins the layers of ethnographic description that continue through chapters five, six, and seven. Finally, chapter eight and nine uncover the common patterns and therefore the cultural norms, whilst chapter ten discusses the findings and seeks to make sense of these for patients.

**Prologue:** The thesis begins with a prologue, that is, a stark personal narrative that needed to be placed up front before I could accept and situate myself in the position
Chapter One: Introducing the Research provides an overview of the thesis which is an anthropology about nursing, grounded in the autobiographical experience of the researcher as a nurse and patient. The research sought to understand why patients submissively accept compliance in the nursing relationship and, to understand this phenomenon, an anthropological perspective about nursing was sought. The aims were to capture information which is at risk of becoming lost, to capture the meaning patients attach to nursing and to describe the expected behaviour and the pathway through health culture for a person who becomes a patient.

Chapter 2: Setting the Context provides the background rationale to the research, based on my personal experience as a nurse, and as an insider to the world of being a patient. Historic, economic and sociological backgrounds in which nursing takes place, are then drawn out through various forms of literature to present an integrated in-depth understanding about the context in which nursing occurs. Further discussion reviews society’s dominant imagery of nursing, and the dominant discourses in nursing literature about being nursed. Additionally, fictional literature is explored as a means of cutting through taken-for-granted nursing knowledge and conveying meaning from patients’ perspectives. Literature also provides an historical overview of nursing in general and, specifically, nursing in Australia.

Chapter 3: Situating the Self & the Underpinning Philosophy of the Research begins by situating myself as the first person researcher within the context of the research process. The philosophical underpinnings of the thesis are examined, firstly through the distinct phases of the autobiographical self; secondly drawing out those values that I believe ought to direct practice; and thirdly, moving to hermeneutic philosophy that underpins the methodology of anthropology and the ethnographic process. These positions are complimentary, underpinned by the notion of humanism which acknowledges each person as being of intrinsic worth.
Chapter 4: *Methodology* discusses the anthropological perspective and the use of ethnographic processes. Technical terms are defined, beginning with anthropology as the academic discipline of the study of human kind in their cultural setting (Seymour-Smith, 1986), which is linked to ethnography as the processes that are utilised to gain an anthropological perspective. This chapter provides an in-depth appreciation of the historical underpinnings of anthropology, an exploration of the concept of culture and why culture is so powerful, and discusses the attributes and methods of being in the field, participant observation, multiple forms of data and analysis. Finally, the attributes of ethnography are expounded upon, and an overview of the research design is detailed.

Chapter 5: *Being in the Field*, begins the ethnographic text. It is a narration about the logistics, the experience, and reflections on the experience of undertaking fieldwork and participant observation. It begins with description of the broad cultural landscape, giving due recognition to the physical and social environments, focusing on rural communities, district nursing, and health structures in rural Australia. Various formal and informal pathways of access are detailed, from formal negotiations through ethics committees to informally seeking positive participation. Layers of data emerge in the form of fieldnotes, journaling and reflective journaling on which the following chapters are based. Finally, methodological issues such as the fine line of being in the field as a researcher in one’s own culture, and reflections about this process are explored.

Chapter 6: *The Nursing Narrative*, moves the ethnographic text from the focus of undertaking fieldwork, to a descriptive dialogue about nursing, thus revealing another layer of the culture. The framework of a nursing day provides the structure to describe what nursing is about, through the voices of nurses, patients, and the researcher’s reflections. Predominant images are then ‘flip sided’ so that they are viewed from every possible perspective to avoid only the dominant being seen and made public. The dialogue reveals a variety of subjective experiences of nursing and being a patient, providing insight into nurse-patient relationships and nursing needs. As a narrative, it reveals the mundanity and the uniqueness of home nursing, as well as the complexity of meanings of being nursed and many dimensions of nursing.

Chapter 7: *Patients’ Voices* is the third layer of cultural description. The focus has now moved from nursing to being nursed as the narratives now focus unconditionally on patients’ perspectives. The inquiry revealed that the meaning patients attach to the experience of being nursed is fundamentally different to that of nurses. Patients attach specific meaning to their individual situation; they have different beliefs,
values and expectations; differing concepts of themselves, their illness, and their nursing needs. As with nursing narrative multiple realities and meanings emerge as people who are recipients of nursing struggle to find a position which is accepted by the nurse, cultural norms, and their own wants and needs.

**Chapter 8: Patients & Health Culture: Time and Space** moves the ethnography to a complex cultural analysis that illustrates the power of culture. The relationship between cultural constructions of meaning, expected patterns of behaviour and being a patient now become evident as the layers of culture are integrated, inclusive of the structural and political environment, the nurses’ day and patients’ voices. Notions of time and space were found to be constructs of being a patient that shape the illness experience, whilst deviations from the norm then shape the ongoing experience of being a patient. Together, time and space shape the pathway a patient is expected to follow, the meaning of the experience of illness and, as a consequence, the patient’s sense of self.

**Chapter 9: The Cultural Norms: Shaping Patients’ Experiences** illustrates the social construction of the illness experience and, as a consequence, enhances understanding of the cultural issues that give meaning to and shape the experience of being a patient. The discussion begins with an exploration of the biomedical model as the dominant social norm which gives meaning to and shapes the norms of health, wellness, and health culture. Secondly, given this medical model which converts people to patients - where it is the norm to be passively compliant with medical advice - the role of nursing is re-examined. Nursing was found to actively support the biomedical model of health, leading patients through the various norms of medically orientated health culture. Finally, this chapter looks at how society and nursing continue to further reinforce the medical norms by constructing a patient’s experience, and then, how the reactions of society and nurses towards patients perpetuate cultural norms.

**Chapter 10: Making Sense of Health Culture** draws the thesis to a conclusion. Firstly, the findings draw out the insider-outsider contradictions of health culture where the dominant view, or cultural norm, is the outsiders’ view. An outsider looks in without being able to appreciate the nuances, therefore they are unable to appreciate the complexity of being a patient. Secondly, the conclusion summarise why this has occurred, by looking at the roles of those who participate in this culture. In particular, the discussion re-looks at the role of nurses. The nurse-patient interaction is shown to limit patients’ responses in nursing interactions - it is a form of sanctioning that reinforces nurses power differential over patients, whilst nurses
actively participate in leading patients through health culture. Next, the process of being a patient and being moved through the stages of health culture is discussed and a map or pathway through health culture and the associated rules are described. Finally the discussion contrasts nursing theory underpinned by humanism and respect for persons with the role that nurses accept, that is a role which reinforces cultural norms.

**Summary**

The research is a reflection of my career and the dilemmas constantly faced, perhaps eloquently reflected in the phrase ‘a person becoming a patient’. The dilemma is in seeing and knowing that, regardless of nursing theory, education and knowledge, nursing partakes in the process of people being converted to patients, yet the paradox persists as nursing is espoused as a humanistic profession.

As the introduction states,

... when injury limited me to the singular status of being a patient, I encountered the experience of being confined to implicit expectations of benevolence, paternalism and dependence. I became an insider as I experienced the world of being a patient as only participants can appreciate.

As a consequence of this experience my endeavour throughout this thesis is to uncover the culture of nursing, to come to understand why patients experience, and accept, this subservient position. The benefit of the research is intangible as it is about understanding and enhancing the philosophical base of nursing by explaining the world of nursing from the perspective of being a patient. The research is therefore grounded in an exploration of practice that directly links humanistic theory with nursing practice and with a personal and professional belief that nurses and nursing must value humanistic interactions.
This chapter demonstrates the historical, economical and sociological milieu, that is the socially constructed layer of our environment, that shapes and gives meaning to the culture of nursing. Four types of insight are drawn upon to set the context for the research. These are: the background questions that led to this research, literature as an artefact of cultural knowledge and as a means of cutting through taken-for-granted knowledge, a review of society’s dominant imagery of nursing, and an exploration of nursing and history, specifically to look at nursing in Australia.

Background Rationale

The rationale for this inquiry emanates from two distinct levels. The first level is the personal experience as an insider to the experience of being a patient, within the context of the community. Viewing the experience of becoming a patient in a community or cultural context enabled an appreciation of individuals and roles; how our roles are given meaning and value by the community and, in turn, how the notion of community also shapes the roles of participants. The second level was to appreciate the discursive nature of nursing practice through the notion of the self as the first person researcher.

The insider's experience

Anthropological inquiry is grounded in the emic or insider’s perspective. By becoming part of the culture the anthropologist has the potential to achieve a level of understanding that would be impossible by any other means (Barrett, 1991; Miller, 1991; Spradley, 1980). In addition, personal experience adds further depth of meaning as the researcher is innately part of the culture being studied. This dialogue is written from the autobiographical experience of living in a rural community, being a patient, a nurse and a woman. The demographics of rurality revealed relatively closed communities and, consequently, nurses balancing the intricacies of their roles within the community. Nurses are privy to the confidentiality of people’s lives and
therefore their roles (as nurses, women and community members) are entwined, as are their private and public lives. Nurses, patients and community are not separate entities. Each is integrated within the broader context of the society in which we live, function and interact. As Bowers explains,

Social events and situations do not have meaning in themselves. ... They are defined by the participants, placed by them within a structure of recognised and mutually known practices, continually defined and redefined in the interaction progress. They are also reflexive. They are not only shaped by the social structure, but they also serve to create and elaborate that social structure (Bowers, 1992, p.60).

In this context, I sought to understand the experience of participants as they were subject to the expectations and norms of a variety of roles.

Injury meant I (unwittingly) became a patient as the injury resulted in illness and permanent impairment. Over time, without any conscious realisation, my role moved from being a nurse with a comfortable status that encompassed who I was and a contributing role in the community, to being a patient. With this, I lost my sense of personal value due to expectations of submission and compliance. As my position changed and I could no longer convert to the public imagery of the nurse, the cultural norms of expected compliance increased and, as a consequence, who I was took on a different persona. I knew from my own nursing practice that this was not an isolated experience, rather, my prior, tacit and taken-for-granted knowledge, suggested it was more akin to the norm. Realisation that this experience was a common phenomenon therefore located my personal experiences within the concept of culture, given that patterns of behaviour are learnt and give meaning to social situations, that shape and are shaped by the norms of the culture (Merrill, 1969).

The discursive nature of nursing practice

On a broader level, the rationale for the research was grounded in the discursive nature of nursing practice as being an insider also forced me to confront other taken-for-granted and accepted ways of nursing that disregard patients’ individuality and integrity. For instance, this research is written at a time when nursing professes to be a profession that is grounded in a body of unique nursing knowledge and the philosophy of humanism, yet nurses struggle with a multitude of conflicting expectations.

For example, the ambiguity entrenched in nursing language highlights the disparity between the meaning imputed by nurses and the meaning inferred by patients. Terms that imply that nursing emanates from patients’ expressed needs are patient
autonomy, ethical practice, patient advocacy, patient participation, wholistic (holistic) nursing, patient centred nursing, and even nursing care. Nursing now occurs in the health care system (that was until recently referred to as the medical system) and nurses provide nursing care (as opposed to nursing or nursing actions) for patients. But is this the patient’s experience? Do nurses appreciate what their language implies? How does the disparity fit with nurses’ clear articulation of the fiscal and time constraints by employing institutions? As a nurse and patient, I find it incomprehensible. How do feelings of submissive compliance fit with the emotive moral implication of ‘to care’, implying the patient, their values and their personhood, matter?

Tensions between the rhetoric of what nursing language implies, and its use in practice to imply something rather different, may be explained by dominant public imagery that permeates nursing practice and the hierarchy of the health system. Nursing practice is shaped by others, such as the medical profession, and nurses accept this status quo, focusing on patients needs which are prescribed by others, whilst patients are grateful for any assistance. Additionally, nursing practice is grounded in the assumption that nurses know, or at least listen, to what patients want, and that nurses have the autonomy and resources to meet expressed patient needs. It is also grounded in the assumption that patients will tell the nurse what their needs are and ignores the social constraints on nurses and patients. This point is reinforced by James (1992), who looks at the socialisation of new nursing graduates, noting

... the qualified nurse saw her main function as assisting and supporting the doctor, [with] a deep loyalty that was related to her desire to stay in the team. The price paid for membership was subordination (1992, p.19).

Conflict is also implicit in the individual nurse’s way of practice, for example, between intrinsic satisfaction, a caring morality, or working for the income, as exemplified by the post industrial revolutionary attitude where work is related to earning a cash income and “... the nature of the work takes on a less important place” (Geddes, 1991, p.145). Additionally, nurses, and the actions of nurses, are the visible public image of political rationalisation of the health system.

**Issues of control that shape practice**

Nursing, then, is quite clearly controlled by social norms and political policies rather than professional ideologies. The focus of health policy and funding is on physical activities performed in a given time frame and nursing is costed and funded from the number of patients seen, which is a practice that disregards and silences the complexity and individuality of nursing needs and nursing provided (Keyzer, 1993).
Nurses are the interface between health funding and the public as they allocate scarce resources in accord with social and political policies. The risk of not doing this or attempting to bring about change, is to risk their employment.

Government policy is delivered on a public level but people only tend to realise the implications when it affects them personally. On one hand, nurses are on the lower layer of the health care hierarchy and have been limited in influencing health policy. Conversely, nurses spend more time with patients than other health professionals, hence, merely as a consequence of their role, nurses are the public interface between health funding and scarce resources. In turn, the public imagery of nurses inevitably impacts on the nurse as an integral part of the community, and an accessible health professional.

The prevailing discourse reveals nursing practice is subjected to conflict; by social and political policies and the shaping of nursing by government policy, funding bodies, the medical profession, institutional policies, laws and employing bodies (as described in Evans, 1986; Gardner & McCoppin, 1989; Johnstone, 1989; Salvage, 1992; Trueman, 1990). In contrast, the profession of nursing is ideological, shaped from a unique body of nursing knowledge and underpinned by the philosophy of humanism, implying action “... in which human interests, values, and dignity are of primary importance” (Paterson & Zderad, 1976, p.85). Nursing practice is subjected to a variety of cultural norms and expectations that force nursing to exist within a dichotomy, accepting and practicing from conflicting tenets.

**How nurses adapt**

As previously stated, I do not accept that nurses per se do not practice with patients’ values as central to the notion of nursing care. The prologue, for example, reveals my own struggle to accept patient’s values as a central tenet of practice. I believe that some nurses practice with a caring morality where patients’ concerns are central to practice. Others believe they do, but observations and patients’ concerns indicate otherwise. There are also those for whom earning an income is the central concern.

Nurses have adapted to the pervasive forces that control and shape practice in various ways. Some do what they can in work hours and continue to provide nursing within their personal time; others have reclaimed authority of nursing work, practising with independence or autonomously, by not seeking or accepting subordination (Martin, 1989; Wicks, 1995). Some accept the given dominating structure and some resign. Others actively participate in the domination and find their power through subordination to doctors and, in turn, assume the right to control the people whom they nurse.
The cultural norm and common belief about nursing and what nurses do, reveals discursive and problematic expectations, as nurses work as professionals whether guided by patients’ values or subordinated to the medical profession and health politics. As a result, what is expected of both nurses and recipients of nursing is not given clear expression, rather, participants receive conflicting messages, dependent upon the sender.

**Implications for patients**

So what does all this imply for patients? The broadest overriding implication is that of power in a capitalist system. For example, in our capitalist system, government policies and funding control the very nature of health services and what is possible in a given circumstance. Capitalism espouses equity and fairness whilst being based on the contradictory premise of competition (Thornton, 1990). Likewise, nursing practice in a capitalist society is subject to economic and social ideologies that dictate normative actions, which, in turn, conflict with the professional and theoretical base of nursing.

There are also other aspects to this notion of conflict between nursing and cultural norms. For example, is the concept of patients’ values as central to practice culturally acceptable? Are nurses themselves in a position to enact this ideology? In addition, when a patient seeks out nursing they are in a position of need; need makes a person vulnerable (Irurita, 1999). Vulnerability is further increased as nursing is inevitably about peoples’ private bodies, private lives and takes place in the private sphere of our culture, thereby breaching cultural norms (Altman & Chemers, 1980; Lawler, 1991). Altering the cultural norms of privacy alters the dynamics between people and so the nurse-patient relationship exists within an unequal power base. Similarly, patients are in a position of need. In meeting nursing needs, cultural norms of privacy are breached and as the private domain of culture, nursing is not legitimate conversation. As a result, what occurs and the feelings and meanings attached to experiences of being nursed remain silenced - they are culturally sanctioned.

Authors such as Illich (1976), Irurita (1999), Lawler (1991) and Stockwell (1984) describe the implications for patients who breach the norms of the sickness role or who fail to value helping professionals. It is a stark reality that nurse-patient interactions are frequently problematic and that this will remain so while patients cannot voice their needs or opinions without risk to themselves. This research and personal experience demonstrates that patients rarely struggle; they accept the status
quo rather than risk their senses of self or their allocation of nursing time, as they are vulnerable within the norms of society.

The tendency of patients to accept a passive persona is also a discourse exposed in phenomenological and sociological literature, alongside autobiographical and fictional writings about the experience of being nursed. These are inclusive of Whose Life is it Anyway? (Benedictus, 1981), A Very Easy Death (de Beauvoir, 1964), This is what we have to do are you ok? (Gibb, 1990), The Diaries of Jane Somers (Lessing, 1983), Cry of a Damaged Man (Moore, 1991), Pride Against Prejudice (Morris, 1991), Awakenings (Sacks, 1990) and Good and Bad Patients (Stockwell, 1984), to name but a few.

**Literature as Cultural Knowledge**

As this inquiry pursues an anthropological perspective, it is not the norm to undertake a literature review, rather, the perspective is one of naive realism where the knowing is learnt directly from the culture. Anthropology does, however, naively learn about a culture by studying cultural artefacts. Consequently, fictional literature, scholarly literature and various documents are drawn on as artefacts of cultural knowledge which contribute to the ways of knowing.

For example, Elizabeth Jolley remarks on the commonality of anthropology, literature and nursing, as she reflects on her career as a nurse and an author, explaining “[b]oth require a gaze which is searching and undisturbedly compassionate and yet detached” (1992, p.51). In addition, literature has the ability to reveal, and make obvious, aspects of the culture of nursing that are not spoken about. Subsequently, documentation, notations, reference text, prescriptive manuals, stories and reflectivity were accessed as artefacts of nursing. Fictional literature was also accessed as a form of expression that has the ability to disclose dominant public stereotypes and bring these into question, due to the freedom of such literature to mirror people’s realities (Younger, 1990). As Bartol explains, literature has a humanising effect “… awaken[ing] us from the numbness that all too frequently accompanies routines” (1986, p.23).

Literature alerts nurses to revisit notions of patient-centred care whilst revealing that these notions are not generally the experience of the patient. A strong body of research, autobiographical, biographical, fictional, phenomenological and sociological literature, calls on nurses as intimate carers, to appreciate how illness, or being in need of nursing, impinges on a person’s access to the world.
As Kretlow explains,

... illness [brings] with it, often for the first time, the realisation that the body is the means not only of accessing the world but also the vehicle of the self (Kretlow, 1989, p.9).

As an artefact of cultural knowledge, literature endeavours to impart an appreciation of the disparity between perceptions of being nursed and the rather sinister experiences of being a patient.

**Reviewing the literature**

Literature was reviewed as cultural artefacts, but also to advance an appreciation of the value of anthropology to nursing, to broaden my insight into the methodological process, and to reveal the current state of knowledge in the area of the study.

An initial review uncovered no articles related to Australian district or domiciliary nursing, what these nurses actually do, or the perspectives and feelings of patients. A number of articles originating from foreign countries, related to home nursing and patient perceptions, were located, but there were quite different constructs of health and health services and therefore these did not contribute to this study. Nonetheless, reference lists, bibliographies, and other serendipitous findings were pursued, leading to a broader focus on nursing, sociology, and culture.


In various ways, all of these writings furthered my understanding about culture and have contributed to my appreciation of the cultural construction of meaning related to health, nursing, environments and society.
Dominant themes from the literature

Firstly, literature reinforced my pre-existing concerns that many nurses fail to grasp the meaning attached to the experience of being nursed and fail to appreciate a user perspective (Caldock, 1994; Draper, 1992 a, b; Gibb, 1991; Irurita, 1999; Morris, 1989, 1991; Rawlinson, 1999).

Literature revealed a long history demonstrating the divergence of the perceptions of needs held by participants. Nurses were (generally) perceived to have the right of defining both needs and appropriate responses, with priority on a routine, efficient manner of nursing (Caldock, 1994; Featherstone, 1982; Gibb, 1991; Littlewood, 1987; Lorber, 1975; Stockwell, 1984). Little has changed. In 1999, Irurita notes that “[q]uality studies frequently focus on professional standards and expectations only, overlooking consumer satisfaction” (p.10).

In a similar vein, the literature revealed a divergence between the perception of needs held by participants and health professionals, revealing a theme dominated by the altruistic attitude of health care providers (Ashworth, Longmate & Morrison, 1992; Holmes & Warelow, 1997; Illich, 1977; Jourard, 1971). Literature also highlighted the underlying assumption that the nursing assessment and the needs of the patient are synonymous, disregarding the power differential innate in caring professions (Holmes & Warelow, 1997; Jourard, 1971; Littlewood, 1987; Ong, 1991; Ross, 1987).

Secondly, nursing work is silenced and as a consequence, concrete instances of nursing remaining elusive.

The first sub-theme is about cultural sanctioning which silences nursing. Lawler (1991) exposes the silencing, invisibility and illegitimacy of any conversation about the essential nature of nursing because nursing is about private, intimate interactions on private bodies. The private invasive nature of both nursing work and, the experience of being nursed, therefore mean that nursing is a breach of cultural norms; nursing is silenced because it is culturally sanctioned as illegitimate conversation.

In the second sub-theme, literature refers to nursing as ‘dirty work’ (Davis, 1984; Jeffery, 1979; Littlewood, 1991), that represents an image of someone who handles socially less desirable things such as bedpans (Somjee, 1991). The social consequences and implications of society regarding nursing as dirty work, and therefore unrespectable, is that the nature of nursing work is silenced (Davis, 1984).
Czechmeister captures the essence of nursing being culturally sanctioned as dirty work, as society’s construction of meaning, from Lawler’s study.

The nurses ‘sustained and intimate contact’ with people who need help with their body care, in a society where the body is taboo and body products are symbols of dirt, renders her work socially misunderstood, undervalued, unmentionable ... (Czechmeister, 1994, p.1231).

In the third sub-theme, nursing is silent as it is based on taken-for-granted and intuitive knowledge (Cash, 1993; Davis, 1984; Lawler, 1991; Lorber, 1975; Meerabeau, 1991; Wicks, 1995). The literature reveals a paradox, as these ways of nursing and nursing knowledge are difficult to capture in words, yet hold the essence of nursing as an interpersonal interaction and, thus, meaning from patients’ perspectives. The knowledge base that reflects how these actions are performed is the aesthetics and artistry of nursing which remains within the tacit and intuitive dimensions (Meerabeau, 1991; Polanyi, 1958).

Finally the literature reveals the consequences of silencing. As what nursing is about is not public knowledge, nursings’ public imagery is what society chooses to believe. Kalish & Kalish (1987) suggest nursings’ imagery is an extreme divergence from reality and, consequently, what occurs in nursing is open to (mis)interpretation and a lack of understanding about the reality of nursing and being nursed. Silencing perpetuates the devaluing of the nursing interaction. For example, subsuming language such as ‘basic nursing care’ secures privacy, yet hides the complexity, social and financial significance of nursing interactions (Keyzer, 1993; Morrison, 1991). Likewise, as Parker & Gardner explain,

[although a nurse may spend an hour sitting with a patient, talking, coaching and helping, this is not likely to be recorded in the patient’s progress notes (1991, p.6)].

This quote exemplifies how oral traditions of nursing have resulted in the devaluing of nursing interactions, whilst also typifying the contradiction between espoused theory and the reality of acceptability in practice.

Thirdly, the literature exposes the labelling of patients by the health care system, demonstrating an unequivocal link between a positive category of patients with compliance and obedience (Jeffery, 1979; Lorber, 1975; Stockwell, 1984).

Lorber’s study (1975) for example, confirmed that patients tended to accept the general norms of expected roles. Patients conform, in spite of resentment, because
they feared the consequences, such as being crossed off the books, receiving less attention to their needs or being made to feel a nuisance. Those who asked questions, who did not fit with the routines, or displayed unacceptable behaviour, such as unrelieved pain, were deviant, problem, or bad patients (Stockwell, 1972, 1984). Kelly and May concluded that the labelling and expectations were of concern.

The role of the caring nurse is only viable with reference to an appreciative patient. Nurses symbolically take the role of the patient both to make and to make sense of, their own role, and it is in so doing that the labelling of patients inevitably takes place. The good patient is one who confirms the role of the nurse, the bad patient denies that legitimisation (1982, p.154).

Labelling takes on an even more perverse connotation when medical professionals refer to patients’ actions, in consulting them, as using the medical system to get medical certificates, to enter a sickness career, and to enter the sick role that legitimately excuses people from normal social roles (see Alexander, 1982; Friedson, 1960). In stark contrast, in an anthropology about nursing, Littlewood (1991) explores the value of nursing in managing ambiguity, and mediating between a person who needs nursing and the outside world, as being central to the notion of caring for persons.

*Finally the literature debates the ambiguous and flaunting use of language.*

One example is the use of the word care. Care is used as an adjective to convey the way nursing is provided whilst it is also used simply in reference to nursing actions: to undertake nursing actions has become to care. We have nursing care, health care, carers, or nurses providing care. Whilst debate surrounding the essence of the word care continues by authors such as Ashworth et al. (1992), Kitson (1988, 1992), Leininger (1988) and Watson (1990), care does not necessarily imply special moral values. One definition of care in the Oxford Dictionary (Turner, 1987, p.150) is ‘to do for, to provide for, or, to look after’. In addition, studies by Brown (1986) and Larson (1984, cited in Morrison, 1991), found that perceptions of caring attributes were quite different between the nurses and patients. The dilemma of language is grounded in nursing jargon where common language has been hijacked so that the meanings imputed to many terms differ from the meanings patients attach to the language.
Contrasting perspectives in literature

This literature enabled me to understand some of my nursing dilemmas and yet I could not accept that nurses misused power so blatantly; I believed that I had practised with patient needs as the focus of practice. This may not have been the norm, but I also knew that it was not uncommon and I was not alone. Contrasting literature highlighted the will of nurses to provide wholistic care, unique to each patient, their needs, values and life styles, with nursing grounded in morality. This was summarised in the theme:

_The art of nursing is compassionate caring, involving the empathetic understanding of what an illness or condition means to a person. Values as cherished by others ought to be accepted and respected by the nurse simply because a person, as a human being, is identified by the values that they uniquely set store to_ (Carper, 1978; Curtin, 1979; Griffin, 1983; Oakley, 1992).

Nursing scholars have highlighted the nature, effect and potential of nursing as humanistic practice (Benner, 1984; Benner & Wrubel, 1989; Cox, 1996, 1999; Gaut, 1983 and Taylor, 1994). Caring ‘about’ is a reflection of the patient’s needs and is individualised and anticipatory; the need may be anticipated, but it is more than this - it involves the nurses responsive expression, reflecting the manner in which the nurse cares for the patient (Benner, 1984; Benner & Wrubel, 1998, Griffin, 1983; Jecker & Self, 1991; Meerabeau, 1991). Caring as the moral essence of nursing is the capacity to perceive, interpret and accept the subjective experiences of others with unconditional worth (Hall, 1993, 1994 a).

The consequence of being a patient

Disconcertingly, the literature has already made it clear, that the stereotypical imagery of a patient may not be so distanced from reality. The paradox of patient-centred care is embedded in the disturbing consequences of non-conformity within the health care system. Likewise, patients are evaluated according to their illness, reputed social class, occupation, appearance, age, attitudes and behaviour, personality, wealth and their status in a rural community (Kelly & May, 1982; Hall, 1994 b). It is arguably perverse and yet, conversely, common knowledge that these social and moral evaluations are ascribed to patients. Therefore, whilst society sees recipients of nursing as fortuitous, how recipients feel is a generalised concept that begs the individuality of patients.
Imagery and reality

Dominant images of nursing practice contrast with the current nursing ideological imperative of respect for persons, humanistic practice and patient-centred holistic nursing. The imagery and the ideology conflict, but what occurs in the interpersonal relationship when the patient and nurse meet? Respecting an individual’s dignity, beliefs, values and actions, (regardless of our own), implies recognition of oneself and of all humans as worthy of respect in their own right (Griffin, 1983). In turn, this enables nurses to provide a certain type of interaction with an empathetic understanding of what an illness or condition means to a person. Respect for persons resonates with the principle of autonomy, respecting another’s values and recognition of a person’s right to choose and follow their own lifestyle. This refers back to my underpinning philosophical position that respect for all persons is central to the art and science of nursing.

Nursing History as Cultural Knowledge

This section illustrates how history impacted on and subsequently shaped the context of nursing in Australia. The ethnography draws on the cultural artefacts of nursing history, initially focusing on England, as the mother country from where our cultural heritage primarily comes. This is followed by an historical insight into Australian settlement; the provision of medical and nursing assistance in the penal colony, medical and nursing assistance for free settlers, then the formalisation of district nursing in Australia.

A broad-brush history of nursing and Australian settlement provides further insight into the ‘organised aggregate’ as the context in which nursing takes place. This acknowledges the development of nursing alongside the nature of Australia’s settlement as a penal colony. To begin with, my historical insight was dominated by English and institutional histories. With such admitted shortcomings, it was crucial to understand the Australian version of nursings’ development from settlement, in order to know who we are and why we do what we do.

Selective nursing history

Authors such as Davis (1980), Francis (1998) and Summers (1975) reinforce the manner in which nursing history is selectively addressed, inevitably revealing a popularist preconception. This narrow perspective alludes to the transference of ‘trained nursing’ from England (as the mother country) to Australia. It is, however, a sweeping version, omitting the experience of convicts assigned to nurse, the nursing
role of free settlers and of women, and the growth of nursing in Australia by lay persons due to the vast, sparse nature of Australian demographics. In contrast, *Australian Colonial Medicine* by Jennifer Hagger (1976) is unique in detailing the development of nursing in Australia, conveying information about settlement, Aborigines and natural remedies, nursing, nurses, patients, the way people lived, and the particular contribution of women. Hagger provides insight into factors that shaped the Australian context, thus avoiding an ethnocentric approach.

**The mother country and nursing**

Dominant historical discourse describes the evolution of nursing in relation to historic, economic and social upheavals; specifically focusing on English history, and the beginnings of nursing with Florence Nightingale. However, I would argue that the history of nursing is embedded in the evolution of civilisation.

According to Summers (1975), in 13th century England, medical training became a university course but, at this time, universities were closed to women. Simultaneously, licensing laws were established which prevented all but university trained doctors from practicing, thereby excluding women. Women healers were stamped out by licensing laws that forbade practice; they were denounced as witches, branded as sorcerers and dispensers of evil, who were drowned or burnt in a relentless campaign. Women could no longer legally practise as midwives or lay healers as had been the norm (Summers, 1975, pp. 44-45). Consequently, the ramifications of history shaped and, arguably, continue to shape, the male dominated institutional nature of medicine and hospitals, and the legitimate role of women in cure and care.

Women were controlled by the value of obedience, with no legal right to wealth or education. Masson (1985) suggests that to escape subordination, the more determined women established careers in communities of nuns, becoming midwives, practising medicine and nursing from a benevolent, vocational position. History equates the beginnings of nursing with wise women and witches, with the domestic duties associated with being a woman, and with women who worked in charity and benevolent organisations. As a consequence, history ignores

... the merits and usefulness of the great body of devoted, though untrained, women who laid out bodies, birthed babies, prepared meals, and quietly went about the many menial tasks demanded by the condition of the sick ... (Masson, 1985, p.15).
Through the following centuries a number of prominent people sought to instigate social change but, as Masson (1985) notes, overall, their impact was negligible.

It was centuries before social reform and respectability of women carers, were achieved. Dominant historical discourse credits the acceptance of nursing at this point in history, in English speaking countries, to Florence Nightingale who established the first Training School for nurses in England in 1860, setting the pattern for modern nursing (Masson, 1985; Russell, 1990; Woodham-Smith, 1968). Nightingale schools continued the evolution of nursing in relationship with religious orders, as a vocational calling involving a sense of duty combined with obedience and subservience. Nurses were expected to practise because of the good it created for others, sacrificing the personal self, reinforcing nursing as a female dominated occupation in a patriarchal and capitalist society; this in turn, aided and abetted the subservient role of women generally, and hence, of nurses (Dolan, Fitzpatrick & Herrmann, 1983; Masson, 1985).

Similarly, Masson suggests Nightingale’s school altered public imagery of nursing.

... [S]ecular vocational nursing ... became identified in the public mind with sanctified [religious] duty, and parents now felt that in allowing their daughters to follow her example, they were doing a service to their country (Masson, 1985, p.63).

The mind-set of sanctified duty may have perpetuated the subservient role of women and set in motion the future pattern of nursing, but it was the beginning of organised nursing. Nightingale nurses were selected and trained specifically for the purpose of training other nurses and nursing practice was finally an acknowledged occupation. Organised nursing, in conjunction with monasteries, convents, and the military, slowly gained acceptance, alongside social changes such as the recognition and value of public health issues.

During the late 19th century, dispensaries and small home visiting programs were initiated in England and America, by wealthy individuals, from an ideology of helping the poor (Dean & Bolton, 1980, p.94-97). The impetus for these was a recognition of public health programs to interrupt the spread of disease. District health nurses worked from dispensaries with advice from a resident physician, and were welcomed as “... their visiting reduced the number of charity patients seeking hospital care, thereby decreasing costs” (Bullough & Bullough, 1980, p.12). There are distinct similarities between the concept of a central dispensary and nurses visiting people in their homes and the emergence of health care facilities for the free poor in the penal colony of Australia, as will be illustrated shortly.
The Australian story

In the midst of the struggle to establish organised nursing, the English settled Australia as a penal colony. The first fleet departed England on the 13th of May 1787, arriving in Botany Bay in January 1788, and it is here that the history of Australian nursing (by white people) began (Blainey, 1966).

As the consequence of a long arduous sea journey, in appalling conditions, many of the crew and convicts were either dead or ill and sexually transmitted disease was rife, by the journey’s end. Once on land, the four surgeons and five surgeon mates who were aboard the first fleet, organised the erection of tents by the ailing convicts. Later, they hired carpenters from the ship’s crew to help the convicts erect wooden huts on the western side of Sydney cove “... [to become] the first hospital in Australia” (Hagger, 1976, p.3). The Second Fleet began arriving in June 1790, with a portable hospital on the ‘Justinian’. This was erected alongside more tents, that were instantly filled with the sick, followed by the Third Fleet later in 1790 and an ever increasing sick population.

The Sydney Hospital also referred to as the Sydney Infirmary (Francis, 1989, p.106), was commonly referred to as The Slaughter House and doctors wore coats “... contaminated with blood and pus which supposedly advertised their popularity” (Hagger, 1976, p.20). In respect of this early hospital, Hagger writes,

> The revolting conditions within these huts [referred to above] were evidently tolerated by the doctors. They knew nothing in those days about disease-carrying bacteria or ‘germs’, or that unsanitary conditions could be breeding grounds for infectious diseases (1976, p.3).

Likewise, Hagger (1976) and Blainey (1966) both state that the convicts who were assigned to provide for the sick were frequently elderly and infirm themselves and only familiar with the unsanitary conditions they had experienced in England.

Australia was a penal colony and nursing began with convicts who were assigned to attend to the sick. They did not do this by choice and did not receive training or pay. “… [T]he nurses received their orders from the hospital doctors whom they obeyed in the manner of servants ...” (Hagger, 1976, p.182). Whilst Hagger and Summers suggest the convicts assigned to attend to the sick were women, Francis (1998, citing Watson, 1911) states the assigned convicts were both men and women, but notes that the women were described as a “... dissolute class who were often intoxicated while on duty”, yet the image of the men who nursed has largely been ignored (Francis, 1998, pp.105-6).
Lay nursing and free settlers

From 1802, immigrants began to arrive, alongside the freeing of convicts who had served their sentence, resulting in a new group within the colony, commonly called free settlers. Schultz (1991) and Hagger (1976) note the absence of any health services available to free people. There was a failure to address the changing composition of Australia’s population as doctors only served the Military Corps. These people, therefore, treated their own illnesses using remedies they had been familiar with in England, sharing knowledge and seeking it from domestic household books. There are also many anecdotes of indigenous Australians, the Aboriginal people, aiding injured white people and conveying their ways of healing, spiritual beliefs, and the healing properties of local plants. Native herbs and plants were commonly used as an alternative form of medicine by free settlers and immigrants who could not, or chose not to access the services of a doctor (Hagger, 1976; Francis, 1998).

Francis notes that the colonial government was simply not interested in providing relief to the free poor and, subsequently, the first benevolent society was founded in 1813. The Benevolent Society of New South Wales dealt with the physical relief of distress. Sydney was divided into six districts, with relief being provided on an out door basis from the six sites. In 1821 with the support of, and a grant from the governor, the benevolent society established The Asylum, to provide shelter to the infirmed and medical assistance to the sick. This was followed in 1826 by establishment of The Sydney Dispensary to provide medical care for the free sick poor in their homes (Schultz, 1991, p.18).

The historical details are sparse, as there is no history particular to nursing, rather one of community carers, self care and benevolent societies. The next mention of home nursing was the founding of The District Nursing Society in 1885 in Melbourne, with the objectives of

... carry[ing] the benefits of skilled nursing medical treatments and comforts to the poor in the city, attending chronic and septic cases which cannot be accepted by the general hospital, completing cures which the exigencies of space have necessitated leaving hospital, and attending cases where removal could entail breaking up of the home (Schultz, 1991, p.339-340).

History tends to focus on the densely populated areas of New South Wales, but fails to address the movement of free settlers into the rural areas of Australia, as explorers, squatters and farmers. Perhaps it was the case, as Hagger suggests, that the injuries
Chapter Two: Setting the Context

and illnesses of free settlers, especially those who lived in the bush, were treated by everyday people out of necessity. Hagger described anecdotes of people sharing remedies; making their own ointments, liniments and tonics, and herbal remedies. Women, as nurturers of their families, and women who cared for their communities, are described as “… compassionate women who came to the aid of the sick with common sense remedies …” to ease discomfort whilst an illness ran its course (Hagger, 1976, p.103). These women cared for others in their communities and were called nurses.

Our nursing history is of women convicts assigned to nurse and, later lay women who nurtured others by providing nursing. The term nursing is, therefore, used with two distinct senses; nursing as undertaken by ‘lay’ nurses and women in general and, later, nursing by ‘trained nurses’.

**Australian settlement and trained nurses**

Rapid changes in the make-up of Australian society influenced by the gold rush, an increasing free population, the war and advances in technology, saw hospitals opening across the vast rural areas of Australia (Russell, 1990). In 1868, a century after settlement, Nightingale nurses were bought to Sydney at the request of the Governor, Sir Henry Parkes, to implement nurse training in an apprentice-like system, based in hospitals (Francis, 1998; Hagger, 1976, Russell, 1990). The benefits of training were espoused as increasing efficiency, better care for the sick, a ready workforce, cheap labour, and a better class of women (Gwillim, undated). This era saw the emergence of organised nursing transferred from Nightingale Schools in England. It was apprentice style training, based in hospitals where nurses were expected to be subservient to doctors and devoted to duty.

Australia’s historical development uniquely shaped and influenced the role of nursing and district nursing, where, as a penal colony run by the military, nursing structures developed, vicariously reliant on the governors of the day. Our history is of women convicts assigned to nurse, women nursing their families and women in communities nursing others. Additionally, the Sydney Dispensary and, later, The Melbourne District Nursing Service provided an outpatient service and visited people in their homes. The history of nursing in Australia and the history of district nursing in Australia are inseparable.
District nursing this century

In Australia in the 1990's, district nursing, home, or domiciliary nursing, refers to the provision of nursing in the home by registered nurses. District nursing services are located and funded in various ways throughout Australia, even with variations between states. For example, the document titled Committee of Inquiry into Nursing in Victoria, (1985), Second Report, District Nursing Services, described three dominant models: discrete nursing units, departments or annexes of hospitals; charitable services; and free standing services such as The Melbourne District Nursing Service.

Throughout rural areas of Victoria, district nursing has historically been a nursing department of a base hospital. As part of hospital organisations, district nursing services have historically mirrored institutional patterns of hierarchies and district nursing practice mirrors organisational patterns that are task orientated.

Currently, district nursing services in rural Victoria still tend to be a nursing unit of a regional base hospital, funded and functioning within hospital policy. They are staffed by nurses employed by the hospital and rostered to work in the hospital’s district nursing service on a dedicated (regular) basis (Committee of Inquiry into Nursing in Victoria, 1985, Second Report, District Nursing Services). Nursing may be provided post discharge as an extension of hospital nursing, or the patient may not have been admitted to hospital but receives nursing from the hospital through the visiting home nurse/s. In this way, district nursing is not a distinct form of nursing practice, rather, the terms are used synonymously as nursing moves in and out of people’s homes and institutions according to the needs or wants of people - or society’s norms.

Reflection on the historical discourse

The dominant discourse of nursing history fails to recognise the role of women who provide acts of nursing as a natural act of humanity. It fails to address limited access to services and fails to appreciate the experience of becoming a patient. When nursing is defined as “... what nurse do for and with people in the course of nursing care ... concerned with caring for people throughout the span of life, and at all points on the continuum between sickness and health” (International Council of Nurses, 1973, cited in Masson, 1985), it can be seen to imply that a nurse is usually a woman, who takes solicitous care of another.
Whatever the definition, nursing is an interaction between two people. When we talk about nursing, the role of the nurse is conferred, yet the role of the patient is, by default, a consequence of the nurse’s role, and therefore is prescribed in these definitions. Ethnographic dialogue draws attention to the language that refers to ‘other’ people, who are ‘patients’, where the nurse provides for these people. It is language that alludes to notions of power and dependence. Definitions are similar to stereotypes in that they reveal much about the nature of these roles (and subsequently the cultural norm for people in these roles) within our society.

Woodham-Smith (1966, p.107) described two totally different conceptions of a nurse from 1850 English history.

[The hospital nurse] ... considered her function was to tend to her patient’s body and restore him to physical health by carrying out doctors orders.

In contrast, there were religious orders and ‘ladies’

... apt to be more concerned with the souls of their patients than their bodies. ... [S]ooth[ing] their souls while they leave their bodies dirty and neglected [as] ... [p]hysical and spiritual were thought incompatible.

In reflecting on the two distinct concepts of nursing, it is timely to relook at the background to this research that describes the paradox of nursing. At this period in time, nursing is costed and funded for physical activities performed in a given time frame, based on the number of patients seen. Current health policy dictates funding formulas and, subsequently, what nurses can do as workers. Due to the limited scope of funding models imposed on the nursing service, it is not surprising that spiritual needs are disregarded and deemed illegitimate practice.

Yet, in contrast, twentieth century nursing theory espouses that the ought of practice is underpinned by humanism. Humanism implies patients are the central consideration of nursing and nursing is about understanding a person’s condition, their response to that condition, and the implications on their life (Benner, 1984; Benner & Wrubel, 1989; Curtin, 1979; Salvage, 1992). The ideological position of nursing theory conflicts with reality. We espouse equity and fairness in a capitalist society and yet we have a health care system that is sustained by competition and constrained by law to follow hospital policy at the expense of individual patients (Johnstone, 1989; Staunton & Whyburn, 1989).

In reflecting on nursing history as a cultural artefact, nursing practice grew from a vocational calling that involved a sense of duty, combined with obedience and subservience. Moving through nursing history to current time, this discussion
suggests that this theme continues to permeate the way nurses practice so that nurses and patients continue to be subjects in a dependent relationship.

**Linking rurality, district nursing and history**

The nature of the history of nursing remains problematic as there is an assumed transference of English history to Australia as an English penal colony, but this was not evidenced in the documentation reviewed. The history of nursing in an Australian context is dependent on convicts, lay carers and principles of self-sufficiency and helping others in the community. Nightingale nurses and nurse training, were not a part of our history until one hundred years after settlement. Australia represented a new way of life, opportunities and challenges in vast, sparse demographics where people relied on each other out of necessity. In rural Australia, nurses, patients and community are integrated within the broader context of the society in which we live, function and interact.

**Other Literature as Artefacts of Nursing**

Literature is an artefact of nursing that enables an exploration of the broad history of nursing, specifically within the context of district nursing in Australia. Other literature, such as nursing texts (Alfaro, 1990) and hospital manuals (Whyte, Baird, Bailie, Cowling and Andrews, 1969), revealed prescriptive literature detailing routines of practice that were printed and regarded in institutions as ‘good practice’, at the same time as texts by nursing theorists proposed the humanistic nature of nursing as directing practice. In this contradictory manner, nursing literature illustrates the underlying conflict evident between nursing theory and what is expected of nurses in clinical practice.

Literature also revealed an archetype of nursing, glorified through themes of doctor-nurse romances, religious connotations of saint-like imagery, efficiency and cleanliness, as self-sacrificing carers of society. Finally this section looks at fictional literature as a way of mirroring subjective realities and bringing into question ways that are taken-for granted. Each mode of literature brings into view yet another aspect of nursing and being nursed, highlighting the ambiguities between images and assumptions by nurses and how these subtly conflict with reality.

**Images of nurses and nursing**

Literature, for example, is a significant means of perpetuating the image of a stereotypical nurse. Nursing’s imagery has connotations of submissiveness,
efficiency, practicality, a woman of knowledge, a woman who has a career and a woman who can make a difference because she helps people. Nursing images are still equated with institutional training where nurses focus on tasks, are organised and efficient, and invariably complete tasks competently in given time frames.

Nurses wear a uniform that traditionally has been their most visual icon and it remains inherently significant. The uniform and the rigidity in the way it is worn is only beginning to change and adapt to the physical demands of practice, with navy blue culottes and white shirts replacing the pure white dresses, although not entirely. Stockings and lace-up or plain slip-on shoes, simple, comfortable and appropriate for a hard days work; short nails, no nail-polish, neat and tidy. These are remnants of the past but remain because they are practical in this line of hard, physical work, and because they still emit an image of nursing with embedded meanings. Implicit in this iconography is an element of pride in who we are.

Imagery is also representative of the woman’s achievements in her career, as badges, stripes and titles reinforce the culture of hierarchial dominance of women by women. Stripes on uniforms and badges all represent the level of knowledge, or rather, their position in the institution which in turn, dictates how much control that person has. That people place an innate value on uniforms and icons was exemplified by public indignation when nurses ceased wearing ‘Nightingale caps’ in the 1960’s, and when starched uniforms (that labelled levels of competence in stripes), were replaced by functional culottes and shirts. Patients expressed concern (and still do) that they could no longer discern who’s in charge, the level of the nurse’s training or even the staff from the visitors. Yet, at the same time, doctors engage in intimate, private conversations and procedures with patients, but they do not wear a uniform and rarely wear coats or badges to declare who they are. Nurses wear uniform, name badges and frequently other badges, explaining it is important to be identifiable when they are entering people’s homes so patients feel safe. Ironically the nurse is also presenting a public image (such as stereotypes) for scrutiny that other health professionals do not perceive any necessity for.

The image of a nurse is important despite changing realities. Society and many nurses hold on to vocational and romantic imagery and so our past continues to impact on expectations by the public, colleagues and employing institutions. A subservient woman is more convenient than a person of knowledge who may challenge a decision, negotiate needs with a patient and be reticent to blindly follow orders.
Fictional literature challenges the dominant imagery

The final theme, looking at nursing culture and artefacts to set the context of the inquiry, is the use of fictional literature. Fictional literature, as an artefact of nursing, provides a means to explore various aspects of practice and dominant images and to bring these into question because of the freedom to mirror people’s living realities.

For example, in the following extract the fictional writing of Doris Lessing portrays the poignancy of the need to respect a patient, their home and their values; or nursing may be irrelevant, demeaning or refused.

... Maudie Fowler one day could not trouble herself to clean out the front room ... Meanwhile she was keeping the backroom and the kitchen spotless. She wasn’t feeling well, and didn’t bother, once, twice-and then her room was not really cleaned, only the floor in the middle of the room, sometimes, and she learned not to look around the edges or under the bed. Her kitchen was last ... then things began to slide. But through it all she washed herself, standing at the kitchen table, heating water in the kettles ... she kept her hair clean. ... Then she left longer and longer between washing her hair ... and then she did not wash her clothes, only took out the cleanest ones there were, putting them back grubby, till they were the cleanest; and so it went on ... But she, Maudie Fowler was still there ... and everything has collapsed around her, it’s too difficult, too much (Lessing, 1983, p.63).

Within this narrative Lessing explains that, in the past, when Maudie was ill, the nurses had come. They said she couldn’t look after herself and put her in a home. Now, as Maudie’s health and house-keeping decline, she does not let anyone enter her home so that she cannot be ‘put away’. In the past, when this happened, her person was not respected and so now Maudie refuses any assistance. Lessing reveals circumstances, feelings and values that are Maudie’s living reality, disclosing scenes not uncommon in district nursing and placing these in a context that challenges nurses to understand and respect patients. Maudie’s past did not represent her present, and so cleaning the house to its former grandeur, or even washing Maudie, would have been demeaning. For Maudie, it would have exemplified what had become of her.

Lessing has exposed us to the society in which Maudie lives and the expected norms of appearance and behaviour, along with consequences of deviation. Maudie had experienced these consequences and escaped back to her own lifestyle. We are also exposed to the insider’s reality as Maudie loses her past ability to care for herself, but one could barely describe this as illness within the medical paradigm. Maudie was ageing. She was struggling to feed herself, but would not let anyone enter her domain, as she had chosen to accept her struggle rather than to be denigrated, taken and shaped into the status quo to meet society’s needs.
Summary

In summary, this chapter sets the context for the research by looking at particular cultural knowledge about nursing and society, which needed to be explored and made explicit, because they give shape to nursing practice and the experience of being nursed. The background issues that initiated this research are dealt with, then the discussion moves to scrutinise various forms of cultural artefacts.

To remember our past means moving beyond the dominant discourse found in political and public rhetoric, to personal knowledge drawn from life experience, nursing practice, and anecdotes from participants, media and historical text. Background issues, along with history, public imagery, the rural environment and the nature of rural communities together with fictional literature are scrutinised as a reflection of society and nursing. They provide a collection of stories about various aspects of this culture, as cultural knowledge that informs the ethnographic inquiry.
This world that I share with others is full of meaning and experience yet everyday life is taken for granted. It originates in my thoughts and actions which have meaning for, and give meaning to my actions, and this experience confirms the reality of the world for me (McPherson, 1987, p.38).

This chapter situates myself within the research, integrating the autobiographical and methodological perspectives of subjectivity and objectivity. Subjectively, my very being is ingrained throughout this thesis as an influence and driving passion, therefore, this chapter makes clear my prior knowledge, beliefs and values, within the context of my nursing career and life experiences, to facilitate objectivity.

Presuppositions concerning the nature of the world and therefore the way I see the world, are referred to as a paradigm, providing the epistemological position that is the relationship between the researcher and participants and their construction of reality. My philosophical position underpins my values, ways of thinking and being in the world, that guide the construction of the research and the way experience and actions are given meaning and interpreted. It therefore shapes the type of knowledge I seek, the methods I use in my research, the questions I ask and the way I interact. The philosophical underpinnings of the thesis are therefore examined; firstly through the distinct phases of the autobiographical self; secondly, drawing out those values that I believe ought to direct practice; and thirdly, moving to hermeneutic philosophy that underpins the methodology of anthropology and the ethnographic process.

Situating the Self

Situating oneself in the research is of particular significance as the ethnographic process is a continuum of researcher-participant relationships where the researcher is part of the methodology and methods; living, participating and learning from the culture under study. Consequently, acknowledging one’s role ought to be explicit to authenticate the research and do justice to the humanness of everyone involved.
Additionally, giving of oneself and one’s own story, encourages and frees others to give of themselves. Reciprocity and the equal grounding of research relationships enhances the ease with which participants feel comfortable being accessed, or making information known. In turn, the level of trust implicates on the authenticity of the information participants can reveal to the researcher about the mundane reality of their lives.

My personal philosophical beliefs and methodological underpinnings are synergistic, enabling an appreciation of the ethical nature of the human endeavour embedded in the researcher-participant relationship that is central to the research process. Denise Donnell Connors captures the importance of researcher-participant relationships as central to interpretive nursing research approaches.

The authenticity of the researcher and her or his ability to become engaged in the research process as a whole person, rather than hiding behind the role of researcher, ... involve an ongoing investigation of one’s own experiences, intentions, expectations, and prejudices in the context of each research endeavour. In the process, researchers can come to a better understanding, not only of the research participants, but of themselves (Connors, 1988, p.34).

**The autobiographical self**

I was a registered nurse, practising in a broad variety of hospital and community settings in both the metropolitan area and rural towns over a fifteen year time span. Nursing enabled me to work with people in a manner that, I hoped, contributed to their well-being. I believed the nurse-patient interaction was the essence of nursing and that valuing patients’ individuality was something I was able to offer patients through my practice: this was an understanding I sought to impart to the nurses with whom I worked. I valued nursing as a humanistic discipline and therefore perceived that practice ought to be grounded in respect for each individual’s personal integrity, and it is from this position that I now reflect on being a nurse.

In retrospect, I was a naive student nurse. I had an embedded belief that patients were people and individuals, and that there was a silent, respectful understanding, that a negotiated compromise took place between the nurse and patient. People who came into hospital needed nursing and medical treatment and therefore it was necessary for them to fit with the hospital system. Nursing routines, available time, hospital routines and patient needs were all compromised by the chaos of the hospital environment. In my naivety, I believed nursing was about assisting patients and the hospital by carrying out measures that would aid a person’s recovery, or keep a
person comfortable. All of this I now find repetitiously scribed in my Preliminary Training School notes and tests that remain with me after twenty-five years.

Six weeks of preliminary training and we graduated as trainee nurses, and the standardised routines and rituals performed on patients, as standard practice, was the dismal reality in which I now took part. Intuitive guilt marked the beginning of my personal conflict as I believed patients were, in all simplicity, people with different values that ought to be recognised. I watched, listened, was directed and acted, and I saw a reality in which people were converted into patients. Being a patient may not sound devastating, but in seeking medical assistance and being admitted to hospital, people’s values and beliefs became non-existent as they were subjected to the values held by that hospital, and the hierarchy of staff, without question.

Journaling and reflection now highlight an incident that triggered my personal pursuit of understanding nurse-patient interactions:-

I was directed by the charge nurse to “... get that patient shaved”. Whilst I willingly assisted people to do something they were unable to do for themselves, perceiving this as a reasonable request, this was not the case. The patient was middle aged, ambulant, self-caring and due for discharge. The outcome of the dilemma for the patient and myself is important although not directly relevant; but the differing values and the imposition of these, not from a need’s perspective, but from a position of power, left its mark. I could not understand why the system, represented by a nurse, insisted a person had to do something against their will, which had no benefit other than ensuring the nurse’s need was met.

I talked with other nurses and friends, but met a blasé acceptance. My thoughts simply did not fit and I could not understand. I recognised I had different values but it was decades before I moved beyond being deviant, assisting or accepting people who were patients in unseen ways; carrying a load of personal frustration and anger about the lack of respect towards the individuality of patients, that was dehumanising of their person. Decision making for patients as a standard part of the culture of nursing practice continued to trouble me. I believed that being a patient does not deem one’s rights as belonging to the nurse. When nursing is a verb, denoting action, the context simply implies that a patient is a person who needs or is receiving nursing, as actions that they would normally do for themselves.
Reflecting on the injury

Years of reflection did not change my values in action but empowered me to accept the philosophy from which I practised. It had begun with confrontational issues, forcing me to question why I could not perform ritualistic practice. Why did it matter to me and yet not to others, what the patient’s values were? How could I work in a system that constantly refused to have an appreciation of, and actually frequently, actively worked against what I perceived as respecting another person? On reflection, I understand that the focus of nursing was to get the job done quickly and efficiently, hence nursing and being a nurse were easier when patients co-operated, were compliant and grateful. The system knew what was best for a patient. In effect, the good nurse met the needs of the institution, the nursing hierarchy and the medical profession; with rewards in ward reports and a smooth relationship with the ward hierarchy.

As I studied I began to comprehend concepts about the health care system and medical culture that constructed the environment in which I nursed. Knowledge helped me to understand this notion of power over another and, in turn, this empowered me to continue nursing practice as I sensed I could make a difference. I knew, in myself, that nursing and making a difference mattered.

Personal conflict now became constructive as I worked to bring about change by example, practicing with a belief that nursing could and ought to respect patients as people, from their value system. In simplicity, this may have meant asking a person when and if they would like to have assistance to shower, laterally addressing my workload to accommodate the individuality of patients. It may have meant stopping my routine and massaging a person, if they appreciated this and if it eased the pain. I knew this if I listened and watched their body language. The difference was in acting to meet the patient’s needs, re-prioritising my workload rather than conforming with ritualised practice. Understanding enabled me to bring about some changes in my own small way. The conflict decreased and I nursed with renewed passion till injury crudely eliminated my ability to physically practise.

Following the injury I experienced the helplessness of having an active mind and a passion to nurse, yet my body had become a separate entity, consumed with constant pain, loss of function and extreme fatigue. But then, it was not merely the physical and emotional grief, but the power of professional helpers, of nurses, that dehumanised my very being, and I soon came to understand the experience of being on the other side, a person converted to a patient.
The fieldwork that is the basis of this research was undertaken three years after injury. In that time, and throughout the following years, I have been a patient by virtue of being reliant on medical treatment and nursing, having a physical impairment that in nursing language resulted in a ‘self-care deficit’ (Orem, 1985). The physical and emotional devastation that encompassed my experience of being a patient strengthened my passion about what it means to nurse, alongside an appreciation of what it means to be a patient. The experience of being a patient strengthened my original belief that nursing ought to complement a patient’s values. Additionally, it now leads me to argue that nurses need to understand the cultural construction of nursing practice, of being a patient, and how the cultural norms of society shape and give meaning to the nurse-patient interaction. At the very least, we need to understand the cultural construction of the actions in which we participate.

**Privileged access**

I was a nurse, a patient and a member of a rural community, and these factors situated me as the researcher and are an acknowledged part of the research. It was quite obvious that I was a patient, as I wore a cervical collar and was limited in my movements. I was aware that my appearance enhanced the affinity some patients felt; it was not uncommon to perceive an attitude of acceptance and, at times, some patients referred to me as *one of them*. Some demonstrated empathy, others talked openly about what being a patient meant *for us*.

Similarly, being a nurse, also provided insight into practice and the silent manner in which one knows what is expected of them, referred to as taken-for-granted, tacit and intuitive knowledge (Benner, 1985; Dreyfus & Dreyfus, 1990; Lawler, 1991; Meerabeau, 1991; Polanyi, 1958). This status and the prior knowing worked together, enabling access to otherwise confidential nursing, medical and institutional documentation and conversations. I was legally one of the profession, as well as knowing the language of the participants, and the meaning and implications that were likely to flow from terminology. I experienced professional and personal affinity, being an insider to both nursing and the world of the patient, and this freed participants of many normal social constraints, enabling me to be privy to a very private world.

My situation as a nurse and a patient hence enabled very privileged access. I remain indebted to the patients for accepting me into their world, their private homes and allowing me to watch nursing of private bodies and intimate bodily functions and, later, to talk about these interactions. The privilege of access can only be fully appreciated returning to the notion of self. It was very difficult knowing I had been
given access because I was a patient but the uniqueness is only captured in the difficulty I had in being reciprocal. As I sought intimate knowledge from participants, they sought it from me. Anthropological research is reciprocal and collaborative - values that are imperative to access seeking understanding in the private realms of people’s lives - yet, I found it so difficult to talk about my injured self. My predicament gave rise to an insight into the value of what patients were allowing me to access - their injured bodies and personhood, and their very private experience. I realised then, that being injured in the sense of one’s personhood holds different meanings for each person, but that, for almost all of us, it was a very private experience.

**My Personal Philosophical Values**

The following stage of situating myself moves the discussion from my personal life experiences that shape my epistemological position, to explore my philosophical beliefs about values that I believe ought to underpin nursing. As nursing inherently involves the meeting of two people, the making of decisions and taking action that affects another, respect for persons is a moral imperative. The philosophical or moral stance of the nurse is found in the branch of philosophy that discerns ‘what ought to be’, that is ethics. Whilst patients may have different world views, nursing as a profession is underpinned by nursing theory such as humanism, hence, regardless of the nurses personal values, there is a professional obligation to respect patients’ values.

This position also acknowledges that patients’ perspectives are variable social realities: they have different experiences, ways of seeing the world, and consequently different beliefs. As Markova explains,

> The world into which we are born is a social world and its continuity is secured through the relative stability of our norms, beliefs, and routines. ... [Through] the process of socialisation, we become oblivious to their existence; we also become oblivious to the presuppositions on which they are based (1978, p.1).

It is therefore timely to explore my personal and professional value of respect for persons, and its relationship to nursing practice.

**The principle of human dignity**

The principle of respect for human dignity is referred to in the work of Immanuel Kant (1724-1804) as an absolute imperative, that is, a value that directs the ought pertaining to situations, decision making and actions (Beauchamp & Childress,
James Rachels (1986) draws on the philosophical writings of Kant to explain that the concept of human dignity is an expression of persons being of intrinsic worth and capable of making their own decisions. Human dignity encompasses the concept that each individual is deserving of respect, hence it follows that people (and therefore patients) are entitled to certain things simply because they are human.

**The principle of autonomy**

Respect for persons continues the theme of human dignity through the principle of autonomy. Autonomy implies respecting another’s values, not because of the good produced from a decision, but simply because choice identifies a person by their values. Respect for individual human dignity acknowledges a person’s right to choose and follow their own lifestyle. It follows that perceptions, perspectives and values as cherished by others, ought to be accepted by the nurse; despite potential incongruities with our own personal beliefs (Beauchamp & Childress, 1989; Downie & Telfer, 1969; Levine, 1990; Young, 1986). In acknowledging that all persons have unconditional worth, an autonomous person, then, is free to discern the course of their own life, having their values respected and regarded as integral.

**The bearing of emotions on morality**

The notion of morality draws together the philosophical underpinnings of nursing practice and my personal beliefs where respecting the autonomy of a person, in turn, respects their very humanness. Concepts that hold together, to develop the encompassing notion of respect for individual’s dignity, are then drawn to a higher level of acceptance and understanding when they become internalised emotions. The concepts inherent in respect, awareness, perception and humanness, are ways of knowing in the ethical sense that give nursing an aesthetic and artistic quality (Carper, 1978).

Awareness of individuality implies recognition of oneself and of all humans as worthy of respect in their own right (Gaut, 1983). This moves respect beyond a philosophical underpinning to an emotion, as it is the nurses internalised self-recognition and belief.

Perception is more than mere recognition. Perception is a cognitive emotion that enables insight and understanding of another (Oakley, 1992). It facilitates empathy, empowering the nurse to feel with a person; to appreciate and show understanding of their situation. Whilst being akin to Gaut’s definition of awareness and the internalisation of a philosophy to an emotion, perception moves beyond respect in the
first form, combining insight into another’s position, looking at the whole person to understand their position.

Humanness is the acceptance of what it means to be human. Levine (1990, p.29) notes that each person is an entity, existing as “… a unity which is interrelated and interdependent”. It is accepted that humans are rational and, because they have this capacity, the implication is that other persons accept and respect a person’s decisions. Taylor (1994) highlights the notion that patients and nurses are connected by the ordinariness in humanity, therefore, because we are humans, understanding and respect for persons is an ideology, an ought of practice.

The emotions of sympathy and compassion enable the connection of feeling with patients, reflecting a shared sense that leads to (nursing) action with respect for the individual’s values. When a nurse is unable to appreciate the nature of suffering, that is, if they lack insight, perception and motivation, it is unlikely that they will accept or appreciate the commonality between nurse and patient or the ordinariness in being human that Taylor (1994) demonstrates as the meeting point of patient and nurse. Not respecting the inherent value of emotions leads to narrow perception and understanding (Oakley, 1992). Respect is not an isolated moral imperative, as to be concerned for another does not necessarily infer action; the nurse must have compassion, empathy and motivation.

Morality and motivation are understood by drawing on the writings of Gustafson (1988). Moral motivation is to do good because the behaviour is sanctioned by society, one’s conscience or ethical judgement. Morality is grounded in respect for individual human integrity; for an individual’s dignity, beliefs, values and action, enabling the nurse to provide a certain type of interaction; based on the principle of regard for persons as subjects rather than mere objects (Gadow, 1989; Gaut, 1983). Moral cognitive motivators are a necessity in order to have emotions such as sympathy and compassion, to perceive another’s distress (Oakley, 1992); whilst innate motivations are nurturing characteristics, such as those of women as explored by Noddings (1984), where caring involves a natural sentiment of caring as well as memories of caring and being cared for.

**Philosophy and the art of nursing**

Griffin moves this discussion from philosophy, to ethics, to practice. Griffin’s practice philosophy appreciates and acknowledges that all humans are worthy of respect as exemplified in the following quote:
Before becoming a patient, he or she was we must imagine, an autonomous person, responsible for his own actions and with a claim to be treated humanely as an end in himself not manipulated as a means to an ends. ... [Patients’ needs matter] ... because part of the very definition of human being is of someone deserving of respect as being of ultimate worth (Griffin, 1983, p.291).

Carper’s (1978) *Fundamental patterns of knowing in nursing*, explains that nursing is an integration of various ways of knowing and attitudes towards another, culminating in the experience between two individuals. The ethical nature of nursing is the essence of when the patient and nurse meet, where human interaction is the art form of nursing, reflected in the manner in which the act of nursing is carried out. The art of nursing is the apprehension of a situation, being aware and open to the knowledge available and alert to the meanings conveyed. This is embodied intuitive knowing, with the ability and courage to discern the situation within the context of the patient, and impart the appropriate knowledge and action to support their needs, within the given circumstances, time and space.

*Being with* rather than *doing for*, are used within nursing literature to draw a distinction between performing a task and performing a task whilst simultaneously setting store to the patient as a person. Synchronicity between the nurse and patient is then referred to as the art of nursing (Carper, 1978). If a patient’s individual integrity is not maintained, a task may be performed with great technical skill (task orientated), without setting store to the patient’s values or respecting their humanness (Benner, 1984; Paterson & Zderad, 1976; Jecker & Self, 1991; Taylor, 1994). The patient’s values as the core direction of practice is a principle espoused by society, The Australian Nursing Council Code of Ethics for Nurses in Australia, health organisation philosophies, mission statements and nursing literature.

**Mundane life patterns**

These values underpin my beliefs about nursing practice. At the same time it is essential to focus on the apparently simplistic mundanity of nursing, as it is the most basic interactions of our lives that significantly impact on our feelings and give meaning to our experiences. Interactions that are described as simplistic or mundane, and are subsumed in the term ‘basic nursing care’, belie their importance to the individual patient. The following exert, drawn from Caplin’s article, *The morality of the mundane*, emphasises a loss of attention to what ought to be.

*It is the small decisions about the content and order of one’s daily life that, when added together, determine something of fundamental ethical importance ... the quality of life. If those who live in nursing homes have*
relatively little control over the content of their own lives, then a critical element of the quality of life - autonomy - will be absent. Our society often gives low priority to questions in health care that bear on the quality of life. For every newspaper story written about the satisfaction of nursing home residents ... 10 are written about the dilemmas of patients and their families faced in the intensive care unit ... [B]ut the seemingly small stakes involved in the nursing home context - setting mealtime’s and bedtimes, use of the phone, the right to keep personal property in one’s nightstand - should not lull anyone into thinking that the daily life in a nursing home lacks either ethical content or importance (Caplin, 1990, pp.38-39).

Mundane life patterns, as described in Caplin’s extract, enable insight into the taken-for-grantedness of nursing, highlighting the importance of simplistic, daily actions and interactions in the meaning we attach to our lives. In turn, the significance of mundane life patterns suggest that this is a fundamental area of nursing that needs to be, understood, and made visible.

Self, Philosophy and Methodology

In addition to the positions already elucidated, I am also situated within the research at the point where my personal experiences and philosophical beliefs meet with hermeneutic philosophy which, in turn, underpins the methodology.

These are all linked by the notion of situating oneself within the research from the premise that, knowingly or unknowingly, one’s norms and beliefs determine and underpin what we focus on and value, impacting on our knowledge acquisition and version of reality. The methodology directs the research process, the way in which one deals with the subject matter, the type of problems thrown up and the methods to be applied in attempting to solve them; consequently the presuppositions underpinning the methodology need to be compatible with my personal philosophical values.

The study utilises ethnographic processes from the qualitative, interpretive paradigm, that seeks to understand human behaviour from the subjective experience of participants. Interpretive research is underpinned by the fundamental assumption of “... understanding the situation from the participants themselves and believing the truth ultimately rests on the direct experience of individuals” (Aamodt, 1986, p.164). It follows then, that reciprocity, collaboration, and respect for participants are methodological imperatives, fitting comfortably with my personal philosophical position. Additionally, the ethnographic process (which is detailed in the following chapter on methodology) is underpinned by hermeneutic philosophy, which seeks understanding directly from the participants through ongoing interpretation of
Chapter Three: Situating The Self and The Underpinning Philosophy: Page 54

experience, expression and understanding in an infinite circle of knowledge acquisition.

**Hermeneutic philosophy**

Hermeneutic philosophy asserts that people necessarily exist within a tradition, in terms of which they see themselves, their world, their past and their future. As the literature revealed, nursing knowledge is not explicit but is found in the dimensions of oral traditions, taken-for-grantedness and intuitive knowledge (Cash, 1993; Davis, 1984; Lawler, 1991; Lorber, 1975; Meerabeau, 1991; Wicks, 1995). Hermeneutic philosophy was, therefore, an important concept underpinning the research as it encompasses experience, expression and understanding with intuition, and tacit, taken-for-granted and common knowledge, along with prior knowing and past experiences (Odman, 1988). Experience and understanding develop from the continuous interaction between these parts and the whole of life, providing ongoing interaction referred to by Odman as the hermeneutic circle or spiral. The intention is for truth to be revealed in mundane reality as understanding develops (Bauman, 1978; Dilthey in Gardiner, 1959; Odman, 1988).

Hermeneutics is drawn from the Greek term *hermeneutikos*, translated as related to explaining, in the sense of clarifying the obscure through an ongoing search for meaning (Odman, 1988). Hermeneutics is the science of understanding others, as the theory and practice of interpretation and understanding (*verstehen*) the nature of people and their social world in various human contexts (Odman, 1988). According to Bauman, in Greek mythology Hermes transmitted the messages of the Gods, announcing them verbatim and interpreting them, to render their words intelligible and meaningful. Hermeneutics aims to enhance understanding from the premise that understanding is fundamental to existence. The presence, design and objectives of human affairs are regarded as purposeful social phenomenon requiring understanding which can only be appreciated by gaining an insider perspective, grasping the meaning or intention invested in actions by seeing through taken-for-granted knowledge (Bauman, 1978, p.12). The basic tenet proposes that the foundations of experience do not reside within the mind of an individual in isolation, but are part of the world of lived experience.

Hermeneutic philosophy discerns knowledge as a continuum; a circle or spiral of understanding of persons and their life experiences. The process of coming to know is referred to as the circle or spiral of understanding, that is
... a perpetual movement from the particular to the total and back to the particular, in order to render transparent what previously, in its uncompromised particularity, was impervious to our interpretation (Bauman, 1978, p.28).

Markova (1978, p.8) summarises the key points of hermeneutic philosophy in the following table:

<table>
<thead>
<tr>
<th>Nature of the Mind</th>
<th>Acquisition of Knowledge</th>
<th>Criterion of Knowledge</th>
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<tbody>
<tr>
<td>The nature of the mind is social</td>
<td>Knowledge is acquired through a circle returning within itself</td>
<td>The criterion of knowledge is internal</td>
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The hermeneutic knowledge acquisition is the process of gaining new knowledge, it is not simply adding more detail to what one knows, but the circle turns in on itself and, with every new detail, the whole of the knowledge changes; nothing remains stable and unchanged.

**An historical perspective**

According to Bauman, hermeneutics can be traced back to early Aristotelian principles of knowing or reasoning, used in the construction of knowledge, which are laws of thought. They do not need demonstration as they are known intuitively through immediate apprehension. The laws of thought state that everything is what it is, and are the very conditions of existence, therefore being ontological or metaphysical. Bauman contends that the laws of formal logic, laws of thought and laws of existence are synergistic conditions of existence that operate. This Aristotelian conception maintaining the unity of thought and reality, is referred to as naive realism (Bauman, 1978, p.24).

Hermeneutical discourse continued to evolve with the philosophical work of Friedrich Ast. He explained that the central confronting thought for hermeneutics is the notion of understanding, that is, ‘to capture the spirit which expresses itself’.

According to Markova, hermeneutic philosophy is understanding, interpretation and the acquisition of knowledge,

... concerned with the *interaction* in the process of coming to know an object in which both partners in the interaction, *both the knowing subject and the object of his knowing* are gradually transformed (Markova, 1978, p.178).

Bauman and Odman refer to hermeneutic philosophy as a blend of nineteenth century philosophies drawn from the German intellectual tradition, inclusive of
Georg Hegel, Martin Heidegger, Hans-Georg Gadamer, Wilhelm Dilthey and Edmund Husserl. Threads of these philosophies are interwoven, forming a general assertion that, whilst subjective meanings, intentions, motives and internal experiences are not accessible to observation, understanding of social phenomena can be developed with a central concern for revealing truth. The following discussion highlights individual contributions to hermeneutical philosophy as used in this research.

Hegel’s contribution forms the basis of hermeneutic philosophy as he asserted that object, knowledge and history, together, form a monolithic unity which is developmental and transcending with time. This was captured in the term hermeneutic circle, which links the researcher and participants and an ongoing dialectic of knowledge acquisition (Bauman, 1978; Odman, 1988). Husserl accentuated the importance of returning to the everyday world where situations and life events occur, emphasising that existence searches for the essence of phenomena and that ‘being’ exists relative to ‘being aware’ of oneself and of others.

Husserl used the terms *epoche, bracketing or reduction* to imply the putting aside of common usage, and holding our attitudes in abeyance to avoid presuppositions (Bauman 1978; Cuff, Payne, Francis, Hustler and Sharrock, 1984). Heidegger and Hegel however asserted that preconceptions are an essential state of ‘being situated’, putting the researcher in tune and open to the things in the world. Heidegger is recognised as returning research to the lived experience of being in the world, asserting that understanding was a mode of being rather than a mode of knowledge (Bauman, 1978, pp.148-9).

Hermeneutic philosophy asserts that people necessarily exist within a tradition, in terms of which they see themselves, their world, their past and their future. An individual can never stand entirely apart and examine a tradition as an object for without it, there is nothing in terms of which understanding can take place (Odman, 1988, p.63).

Human affairs, such as nursing, are purposeful social phenomena. The world exists within multiple realities as we both constitute and are constituted by situations. For example, nursing is part of the world of lived experience. Nursing interactions are both subjectively experienced from an emic perspective and objectified by society as an etic perspective (Miller, 1991). The researcher seeks to capture both ways of knowing and the meaning attached to them. These are viewed in the light of prior knowledge, hence ways of knowing, both knowingly or unknowingly, influence each other and new knowledge and understanding emerges.
From the explanations about the hermeneutical process, as used by Good and Delvecchio (1980) and Benner (1985) in relation to the health care system, symptoms (and hence behaviour) are an expression of the sufferer’s reality, constituting the personal meaning of the illness. The interpretive hermeneutical approach is to understand the meaning of the symptoms/illness/loss of function for the patient. This involves moving systematically from the whole (the broad, cultural description of nursing) through to the part (the interaction) and returning back to the whole (the context, the illness network) seeking comparisons and similarities, to bring to understanding the experience of being nursed from the patient’s perspective.

The underlying assumptions of hermeneutic understanding is that biological dysfunction, referred to as disease, and the human response to dysfunction, referred to as illness, give meaning to each individual’s experience (Benner & Wrubel, 1989). It follows then, that behaviour (the nature of ensuing interactions, such as acts of self-expression, pre-empting nursing routines, non-compliance, compliance, etc) result from beliefs and meanings. As Cuff et al. (1984) suggest hermeneutical understanding is like symbolic interactionism, consisting of meaningful, communicative activity between persons, involving mutual, interpretive work. Meaning resides in an individual’s lived experience and, thus, the hermeneutical model of understanding makes behaviour understandable for the individual.

Hermeneutics encompasses experience, expression and understanding with intuition, tactic knowledge, prior knowledge and past experiences. The constant interaction between experience and understanding are referred to as the hermeneutic circle or spiral of knowledge acquisition “... of endless recapitulation and reassessment of collective memories” (Bauman, 1978, p.17). The focus is for truth to be revealed in the mundane reality as the spiral of understanding develops (Bauman, 1978; Dilthey in Gardiner, 1959; Odman, 1988).

Meerabeau (1991) comments on the unique value of tacit nursing knowledge, explicating the need to understand and allow the life world of practice to make itself visible, rather than impose interpretations. If the research does not go beyond what is observable or spoken about, and does not seek to make tacit nursing knowledge explicit, nursing research is limited. As a consequence, the silenced and non-legitimate discussions and meanings which are known to be highly valued by patients (from personal experience and the literature), cannot be made visible as observable knowledge is not representative of these ways of nursing. Situating oneself as the researcher who is inherently part of this culture is therefore a powerful resource. Without familiarity this ethnography could not convey the nuances of mundane activity that, in essence, enable the opacity and transparency I seek.
Summary

A constant theme has been maintained throughout this chapter, of respect for persons as the ethical, categorical imperative, that philosophically underpins my personal, moral directive. This is a directive that I believe ought to underpin nursing and which does underpin the methodology of the research. My prior life experience and philosophical beliefs have led to the position from which I perceive reality, contributing a unique insider perspective as the basis for the research.

The philosophical position of respect for persons supports active participation and enables privileged access. Pre-existing insight into how this group functions in society then provides a foundation layer of knowledge. Finally, the personal philosophical stance, the philosophical position I believe ought to underpin nursing, and the philosophy that underpins this mode of research are mutually reinforcing. They merge to form levels of thinking, interpreting and understanding.

The reality is that I am part of this research and, methodologically and philosophically, this needed to be accommodated. These principles are reflected in anthropology, using ethnographic process underpinned by hermeneutic philosophy. In turn, hermeneutic philosophy and the spiral of knowledge acquisition is built upon prior knowing, moving to another level of understanding.
If one accepts the assumption that the core of any profession lies in its practice, then to understand that profession it is a necessity to study practice within the contextual setting (Field, 1983, p.3).

This chapter demonstrates why anthropology using ethnographic processes was the methodology appropriate to uncover the type of information sought. An in-depth discussion ensues, linking the methodology with the inquiry and developing an understanding of anthropology, ethnography and culture.

The discussion deals with the methodology, the process and the encompassing methods. It commences with an exploration of the notion of culture, to establish an understanding about what culture is and why it is fundamentally significant in shaping and giving meaning to the way people interact, and therefore to nursing. This is followed with an overview of anthropology as the encompassing discipline that studies human behaviour in context, the process of ethnography which provides the methods to uncover the cultural patterns that are the shared meanings and behaviour of a group, and the attributes and methods of ethnography. Finally, the framework for the research process, that is an outline of the manner in which the ethnographic process is applied, is detailed. Nursing is regarded as a culture and ethnographic terminology, concepts, attributes and methods are described in relation to this inquiry, to enhance insight into an understanding of nurses and patients and their world.

**Why this Methodology?**

This particular study is based on the strand of ethnography that evolved from Bronislaw Malinowski’s (1884-1942) assumptions about people and their social world, and the notion that fieldwork and theorising are inseparable (Cuff, Payne, Francis, Hustler & Sharrock, 1984). An historical perspective, and further detail
about Bronislaw Malinowski’s methods and underpinning beliefs follow later in this chapter but, firstly, it is necessary to appreciate anthropology in relation to the needs of the study.

The discussion therefore returns to the previous chapters which note that an ideal methodology ought to be synergistic with the needs of the participants and also compatible with my personal philosophical position. The fundamental assumptions underlying research from the interpretive paradigm are

... the importance of understanding the situation from the participants themselves and believing the truth ultimately rests on the direct experience of individuals (Aamondt, 1986, p.164).

Additionally, as noted in the introduction, the research sought to appreciate the patient’s perspective in the nursing interaction, with the aim of understanding why patients experience and accept submissive expectations. Given that nurse-patient interactions are merely one interaction which takes place in a complex society, it was necessary to look at the society or culture in which nursing takes place.

The literature reviewed had revealed a paucity of information about patients’ experiences of being nursed, therefore the methodology needed to elicit patients’ perspectives whilst taking account of the power differential that is innate between helping professions (such as nurses) and patients (Illich, 1976, 1977). Simultaneously, nursing and sociological literature suggested that the artistry of nursing is elusive to words, resulting in substantial nursing work not being articulated or recorded (Lawler, 1991; Meerabeau, 1991). The methodology therefore also sought to capture the subsumed complexities, tacit, taken-for-granted, silent knowledge and nuances.

The research hence sought an anthropological perspective, that is, one which seeks to study the everyday lives of a group of people, referred to by Peacock (1986) and Seymour-Smith (1986) as the study of human kind in their cultural setting, to understand the lives of those people (Hughes, 1991; de Laine, 1997). The research is underpinned by the ideology of learning from the people to uncover patterns of behaviour, which are known as cultural norms, and to describe these with a core concern for the people’s perspective (Hughes, 1991; Spradley, 1980). Anthropology’s task is to reveal, make known, and enhance awareness about the culture, the shared understandings that guide behaviour and are expressed in behaviour, along with the taken-for-grantedness and, subsequently, the power of culture in our existence (Peacock, 1986).
An anthropological perspective was a comfortable position to adopt when researching one’s own culture because the focus is disciplinary understanding. The methodology seeks to document and record what is occurring, to make this public and visible, from a desire to appreciate patients’ perspectives of being nursed. In addition, the process seeks collegiality - in this study, nurse and patient participants expressed concern about funding which limited what nursing could occur. The descriptive nature of ethnography consequently enabled the research to meet all these needs.

As stated in the introduction, the overall objective of the research was to understand why it is the cultural norm for patients to experience submissive expectations. Subsequently, the anthropological perspective aims to reveal levels of cultural understanding which are then layered and analysed to enhance an understanding of the experience of being nursed and why patients are submissively compliant.

The broad aims of the inquiry are therefore:

- to expose and make public what occurs in everyday, routine nursing practice;
- to uncover cultural knowledge about the meanings attached to nurse-patient interactions and subsequent behaviour; and
- to enhance understanding of the cultural issues that give meaning to and shape the experience of being a patient from the emic (insider’s) point of view.

It was, however, essential to begin by seeking an in-depth understanding of the concept of culture which leads to an understanding of anthropological methodology and ethnographic processes.

**The Concept of Culture**

To begin with, Spradley clarifies the difference between a social situation and cultural meaning.

[A] social situation refers to the stream of behaviour (activities) carried out by people (actors) in a particular location (place). Culture refers to the *patterns* of behaviour, artefacts and knowledge that people have learned or created (Spradley, 1980, p.86).

The difference is then captured in the following diagram as action becomes a cultural situation.
Merrill (1969) explained culture as the process of socialisation (also referred to as enculturation) as people learn the given patterns of behaviour that assume a uniform pattern. The simplest element of culture is a trait, composed of many individual traits. Traits combine through functional relationships to form dynamic interrelationships. Groups of functionally related traits are known as a cultural pattern, or configuration, which forms the basic functional unit of culture. In turn, human behaviour is patterned and learned, and clusters or patterns of group habits form an organised society.

When a [person] follows the same basic expectations, a degree of uniformity and predictability is observable in their behaviour. They are following the same culture pattern (Merrill, 1969, p.89).

Society then imposes their own sets of patterns upon individuals, assuring (within limits) a minimum uniformity of behaviour. The sanctions that form the moral basis of these patterns are normative expectations (Merrill, 1969). Culture is not behaviour itself, but the shared understandings that guide behaviour and are expressed in behaviour. Groups, then, have patterns of behaviour which are powerful in determining how the group organises their life.

*The Anthropological Lens*, by James Peacock (1986), describes the qualities of a culture that render it powerful. Firstly, culture is powerful because of its taken-for-grantedness. Secondly, culture is powerful because it is shared. Thirdly, culture is powerful because it is communal. The cohesiveness of small communities embodies ritual, ritual sustains belief, and ritual is part of culture, thus illustrating that the community (as apposed to the individual) is the source of culture. The power of culture is then affirmed by the ability of the group to influence personal experience.

With no individual intending or planning it, a group establishes rules, codes, values, and conventions that its members share (Peacock, 1986, p.6).
Studies during the mid twentieth century about the social construction, interpersonal interactions and dynamics in the health care system, clearly note the power of culture, socialisation and enculturation. Coser (1962), McGhee (1961) and Taylor (1972) each depict the socialisation and enculturation of nurses and of patients. They noted that nurses soon learnt the expected way to practice in a particular institution, whilst the reactions of staff reinforced the expected behaviour of patients. Further to this, as previously emphasised, research by Lorber (1975), Stockwell (1984) and Savage (1992) note the consequences of nonconformity, which reinforces the notion of power invested in culture.

Methodological review fundamentally ensured that the anthropological perspective, the underpinning philosophical principles and the ensuing methods of ethnography were appropriate to the needs of the research which was to understand the participant’s world, (not to reform or emancipate). The review found the proposed methodology complemented the notion of understanding as opposed to explanation, with interpretive, non-critical methods revealing tacit, taken-for-granted, and common knowledge.

**Anthropology as Methodology**

Anthropology has been practised for centuries as Western society attempted to understand the lives of others, such as ‘native people’ in non-western countries, focusing on small communities which displayed collective communal attributes (Hughes, 1991; Peacock, 1986). More recently, researchers adapted basic anthropological methods to study smaller groups of people within western culture (Barrett, 1991). Cuff et al., (1984) explain that various strands of ethnographic process and analysis evolved to generate knowledge about local cultures, from theorists such as Boas, Durkheim, Garfinkel, Malinowski, Mead, Radcliffe-Brown and Schultz. These processes are principally concerned with studying interpersonal social interaction, whilst being differentiated by divergent assumptions about people and their social world.

This phase of coming to understand the discipline of anthropology and the processes of ethnography was fraught with difficulty. Literature revealed various sociological, anthropological, and methodological perspectives, referring to numerous strands of ethnography with a degree of ambiguity and interchangeable use of terms. I therefore began cautiously, drawing on the ethnographic framework as explored by James Spradley in *Participant Observation* (1980). Additionally, to grasp a broader appreciation and strengthen my understanding, I drew on Hammersley and Atkinson
(1983) and, finally, as I situated ethnography, I drew on Barrett (1991), Hughes (1991) and Peacock (1986) to explore anthropology as the broader, encompassing discipline of the research methodology.

A review of methodological literature was undertaken, focusing on the key terms of ethnography and, later, anthropology. Methodological literature by authors such as Agar (1982, 1986, 1990), Atkinson (1992), Barrett (1991), Coe (1991), Firth (1958), Germain (1986), Hammersley and Atkinson (1983), Hughes (1951), Hughes (1991), Morris (1977), Murphy (1986, 1989), Peacock (1986), Seymour-Smith (1986), Spradley (1980), and Taft (1988), all strongly contributed to the learning experience and the final, synthesised understanding of anthropology and ethnography and, therefore, in the development of this research. Literature revealed that ethnography is not unproblematic description but one which seeks to enable the truth to become self-evident and transparent, as power and dependence are peeled away and a diversity of voices are heard, rather than purely the dominant (Okely, 1996).

**An Historical Overview: Bronislaw Malinowski (1884-1942)**

This specific study is underpinned by the ethnographic principles espoused by Bronislaw Malinowski. Malinowski’s most noted contribution to ethnography (as the process of seeking an anthropological perspective) lies in his theoretical notion of wholism, where in he asserts that fieldwork and analysis are integrated, that each is meaningless without the other, only gaining significance when interrelated. His concept of wholism also asserts that the researcher must undertake their own fieldwork; in effect, removing the historical notion of fieldwork and analysis as distinct, separate entities (Barrett, 1991; Firth, 1958; Seymour-Smith, 1986; Spradley, 1980).

Culture is defined as the sum of social interactions derived from human behaviour and the products of this behaviour. The material layer of culture includes artefacts and material objects in a particular system. The second layer is the non-material layer, that is, the ideological meanings, values, norms and relationships of the system. The two levels of culture overlay to form a pattern of regularised behaviour (Altman & Chemers, 1980). Similarly, Malinowski described culture as comprising inherited artefacts, goods, technical processes, ideas, habits, values, and social organisation, which are intrinsically inter-related and only meaningful as a whole.

Hatch (1973) and Murphy (1989) draw the following concepts from Malinowski’s definition of culture.
• Fieldwork was of profound importance, focusing on observation of apparently unimportant detail, in the quest for information through quality observation.
• Behaviour was viewed as dynamic, implying that analysis and fieldwork are linked actions in context. Speech, stories, language, or behaviour are all valued, but each is meaningless alone, being context-dependent within the big picture.
• Monistic was the term Malinowski used to describe the nature of human beings, implying that behaviour is a manifestation of natural inclinations or interests, referred to as primary motivation. To Malinowski all people were basically alike. Whilst culture influences individuals, it is necessary to go behind the culture to discover natural dispositions and interests.
• Malinowski focused on the functional anthropological approach, where each part of the system shapes and modifies another part, that in turn, effects another, thus moulding and perpetuating the system as a whole (Murphy, 1989). Function is not the conscious purpose of an individual but resides at an unconscious level. Function occurs ultimately to shape another part of the system at a lower level, to achieve a conscious goal (Hatch, 1973; Murphy, 1989).

**Anthropology and Ethnographic Process**

Anthropology is the cultural perspective (Barrett, 1991), underpinned by hermeneutic philosophy, with the goal of revealing the cultural norms of the group under study. Ethnography is the process and product of gaining an anthropological perspective and, therefore, forms the framework of the inquiry (Spradley, 1980).

The major concerns of anthropology and ethnography are to understand the meaning in human behaviour, from the perspective of participants, by learning from the people to appreciate their life world. Spradley (1980) emphasises understanding through describing commonalities, alternative realities, appreciating silenced voices and bringing them into view; and gaining insight into the mundane aspects of the lives of the culture under study, guided by the principles of naturalism, reflexivity and respect. It is then necessary to make sense of this knowledge and communicate it to others (Hughes, 1991), and likewise, to record distinctive subject matter, nuances or ways of life that may become faded (Barrett, 1991).
Anthropology using ethnographic processes

- complements a personal philosophical stance of learning from people rather than viewing them as participants under study (Hammersley & Atkinson, 1983; Hughes, 1991; Spradley, 1980);
- enables access to meanings that guide behaviour, by seeking to understand and appreciate the complexity of social interactions, from the subjects perspective, within context (Hammersley & Atkinson, 1983; Spradley, 1980);
- develops naturalistic description about the issues through which nurses and patients construct meaning (Hammersley & Atkinson, 1983; Spradley, 1980; Sevingy, 1981);
- enables constant reinterpretation and reflectivity to expand the possibilities of the constructs of knowledge, from what are rigidly regarded as the status quo, to consider perspectives which may have previously been silenced (Coe, 1991; Hammersley & Atkinson, 1983; Lawler, 1991);
- acknowledges the social context of health, as the researcher moves from individual experiences to include social and professional networks which are a larger part of this group (Friedman-Hansen, 1981; Morris, 1977; Spradely, 1980); and
- focuses on understanding, contributing to disciplinary knowledge as opposed to solving problems.

**The Ethnographic Process**

The underlying assumptions of the method orientate and guide the research. Ethnographic process provided a framework, with the rules of inquiry and a given set of techniques, methods and values, to seek to uncover the daily reality and the meaning attached to actions and interactions, with special regard to social structures, individual behaviour, and the meaning of these with respect to the group (Morris, 1977; Spradely, 1980; Taft, 1988).

The methods detailed by Spradley (1980) were employed, utilising the text *Participant Observation* (1980), and ethnographic processes including fieldwork, participant observation. Inquiry is informed by hermeneutic knowledge acquisition through the use of The Ethnographic Research Cycle (Figure 2) and the process of doing ethnography as described through The Developmental Research Sequence (Figure 3). In turn, these direct the nature of the research process, the pathway of data collection, and the manner in which the data is interpreted (Odman, 1988; Spradley, 1980).
The Ethnographic Research Cycle

As open, descriptive research about a culture, an ethnography begins with the collection of data through the observation and recording of social situations, “... refer[ing] to the stream of behaviour (activities) carried out by people (actors) in a particular location” (Spradley, 1980, p.86). An ethnography therefore begins by locating a situation and entry into the culture as a participant, for an extended length of time, learning the culture in the naturalistic environment to come to understand the way in which people see their world. It is about people interacting with one another and their environment, and learning through privileged access as a participant. This way of being enhances the potential of the researcher to elicit understanding and insight into life patterns of the group, to come to understand a culture as the participants do, which would be unlikely by other means (Barrett, 1991; Lipson, 1989). The aim is to understand the everyday world of nursing from patients’ perspectives.

The ethnographic process evolves through The Ethnographic Research Cycle that is now illustrated in Figure 2.
Fieldwork

The researcher moves into the field, becoming a participant in the culture, in order to describe the culture with a core concern for the meanings of actions and events from the people’s perspective. Fieldwork is the dominant and distinguishing feature of anthropology (Hughes, 1991). It is a mode of being in the world, underpinned by the philosophical position where respect for all participants and reciprocity are integral, directing the type of data and the way in which it is collected. As Hughes explains:

What distinguishes the fieldworker from others who move from their own societies to live with another society is not merely the lifestyle but the intentions behind that movement ... The fieldworker ... is a social scientist whose task is to use all the skills and sensitivity which training and aptitude allows to produce a document which will add to the sum of knowledge we have of the almost infinite ways it is possible to be a human being (Hughes, 1991, p.6).

The researcher is situated within the research as the fieldworker, living in the community, participating and sharing in aspects of daily life. Participation over an extended length of time enhances assimilation into traditional, customary patterns, as time exposes or alludes to silenced nuances, enabling the fieldworker to come to know and appreciate a culture and the normative rules which construct behaviour. Participation entails learning to function within the context of the community, transformed into an insider (Barrett, 1991), becoming a participant and an instrument of the research process; observing, recording, identify, interpreting and analysing the culture. The attitude of learning enables enhanced awareness of another’s reality, as the mere notion of learning from another implies valuing and accepting their emic subjectivity and makes possible a unique privileged mode of access. The fieldworker can move beyond the publicly visible facade and imagery.

Fieldwork begins with gathering data by watching, listening and inductively deriving meaning through interpretation and analysis of the field data. The data from fieldwork includes observation about various aspects of human experience, referred to as cultural behaviour, cultural artefacts, and cultural knowledge. Cultural knowledge is what people in a given group know (consciously or subconsciously), and which the group utilise to interpret experiences and, in the creation of subsequent behaviour (Peacock, 1986; Spradley, 1980). The emphasis on cultural knowledge is fundamentally significant as it shifts the focus from people’s behaviour to the meaning of the behaviour.
As the fieldwork continues, the inquiry evolves from grand tour descriptions of the broad social picture, is refined until the basic daily interactions and issues that give meaning to, and shape nurse-patient interactions become obvious. The research moves from the general to the particular, knowledge is refined, more questions are asked and the particular now becomes the general. Fieldwork, analysis of the data and refinement of the focus of the research all take place simultaneously, as illustrated in Figure 3.

The domains of the culture are identified, taxonomic analysis searches for the way the domains are organised, whilst componential analysis searches for the attributes of terms in each domain. Finally, theme analysis seeks the relationship between the domains and how they are linked to the entire cultural scene (see appendix 4). A cultural inventory is elicited from the information and analysis, and an ethnographic text written, which is an insider’s account of the norms of the culture and how these norms give meaning to, and consequently shape the participants’ behaviour (Spradley, 1980). The final phase ensures the hermeneutical spiral of knowledge acquisition and The Ethnographic Research Cycle are completed, then recommenced, as the researcher focuses and re-focuses, reformulating questions, observations and analyses. The circle begins again or is finally completed and the researcher disengages.

**Participant Observation**

Participant observation is a way of being in the field and refers to various levels of participation, from complete participant to complete observer (Polgar & Thomas, 1988; Spradley, 1980). Agar suggests that participant observation provides a situation that makes the work of understanding a culture possible. It gives us an illusive feel for the life of the group, enables contact with group members and gives access to the flow of life from which strips will be abstracted for reflective study. Continual participation and the development of rapport increase the chances that normality is seen, rather than a situation modified for an outsider (Agar, 1982). Participant observation is inseparable from fieldwork when using the underpinning principles of Malinowski, where participant observation and analysis are interwoven and inseparable (Cuff et al., 1984).

Participant observation includes a blend of data collection techniques. In similarity to the notion of being in the field, the observations begin with description, leading to refined data collection, classification and reporting as illustrated in the developmental research sequence.
Although this study uses the framework provided by Spradley (1980) outlined in The Developmental Research Sequence (as illustrated above in Figure 3), understanding this concept is further enhanced by looking at the levels of inquiry as explained by Germain (1986). Germain identifies three levels of inquiry within the ethnographic
research process, focusing on actions, meaning for the subjects, participation by the subjects, description of the nature of relations between participants and description of the setting.

- Level 1: Factor searching inquiry, asking “what is this?”
- Level 2: Factor isolating, explaining, describing and relation searching, asking “what is happening here?”
- Level 3: Factor relating, searching for themes and their relation to the cultural scene, asking the sociological question, “but why is this happening?”

The whole of the ethnographic process and The Developmental Research Sequence (Figure 3, Spradley, 1980) is an interwoven process as the researcher moves back and forth, from data to refinement and analysis, and again, back to the field. Knowledge develops by moving from the particular to the general and back to the particular, in an ever widening circle. Hermeneutic philosophy brings these issues together, asserting that people necessarily exist within a tradition, in terms of which they see themselves and their world (Odman, 1988).

**Ethnographic Terms and Ways of Knowing**

Ethnographic language such as the terms insider, outsider, emic, etic and flipsiding are now explored in depth, as specific ethnographic terms.

**Insider and Outsider**

The terms insider and outsider that were noted in the introduction as their use is ingrained throughout this inquiry, are now explored. Being an insider is about situating oneself in the research and the culture, for an extended length of time. The aim is to become an intimate participant, in order to gain an empathetic appreciation of the participant’s living reality, that is, an insider’s perspective. To truly be an insider who is able to come to appreciate another’s cultural knowledge, the researcher must be open to challenge and reflect on their own basic values, customs and beliefs (Barrett, 1991; Hughes, 1991; Seymour Smith, 1986; Spradley, 1980). As Barrett noted,

> Anthropologists mentally place themselves in their informants’ circumstances, comprehending their logic and value orientations, and in the light of these, assessing their behavioural choice (1991, p.6).

Understanding is to be found in the contrasting notion of outsider. An outsider is like the reader, as they are able to look in at a group of people without the intimacy of
being there. Without having been in the research setting for an extended length of
time, however, they risk making sweeping assumptions, missing nuances, tacit, prior
and taken-for-granted knowledge (Spradley, 1980). In an ethnographic text, an
outsider refers to any person who is unaware of the intricacies of the culture being
studied. Essentially, outsiders look in, but because they are not part of the culture,
rarely are they able to appreciate what it is like. The most obvious example is people
who hold a stereotypical image and perceive any person from a given culture as
fitting the image in their mind. Outsider imagery can be the result of simply not
being made aware of another’s reality or the making of sweeping assumptions, from
media imagery, from ignorance or hearsay. This is also referred to as an insider-
outsider perspective.

**Emic and Etic**

The ethnographic terms emic and etic are also used throughout the thesis. Emic
refers to a subjective perspective, as ethnography focuses on discovering, describing
and accepting an individual’s reality on its own terms. An etic distinction, focuses on
those features that are found to be generalisable, that is, they exist as a predominant
theme or reality, therefore, moving the level of knowing from the particular to the
general (Miller, 1991; Osbourne, 1977). In ethnographic fieldwork for example, data
is collected from an emic (subjective) perspective, whilst as the data takes form, is
refined, and lends itself to analysis, etic possibilities appear (Osbourne, 1977;
Seymour-Smith, 1986, p.92). When a theme, a common pattern, or cultural norm is
found, this is an etic perspective. Osbourne, (1977) reminds the researcher that an
ethnography must appreciate the emic nature of etic concepts, and that etic concepts
must be locatable back in the data.

**Multiple forms of data, data techniques and flipsiding**

The ethnographic approach seeks to uncover every conceivable perspective from the
data, but to do this, the researcher must avoid missing nuances, making broad
generalisations or assumptions, yet they must enable intuitive, tacit and taken-for-
granted ways to become visible. With these goals in mind, the ethnographic process
utilises specific methods - multiple data, data collection techniques, and flipsiding.
Each term is integrated with the other, therefore they are dealt with in one subsection.

**Multiple forms of data** is an acknowledgement that observation, discussions,
conversations, formal and informal interviews, all form a source of data; as do
fieldnotes, reflective notes, reflective journaling, listening, watching, thinking; as
well as artefacts, such as the setting, equipment, objects, the environment, literature,
history and various forms of related documentation. Statistical data, observation and interviews are accepted as complementary, enhancing the richness of qualitative data and maintaining objectivity.

**Multiple data techniques** is the use of participant observation to refer to a blend of data collection techniques, enabling interactions to be observed from multiple perspectives, upon which interpretation and inferences are based. These include
- a combination of data collection techniques, followed by comparison of data relating to the same phenomena;
- the participants are observed from different stances; and
- multiple interpretations are drawn from the original descriptive observations.

**Flipsiding** builds on the multiple data techniques. Description enables analysis, locating social situations within a culture, seeking the meaning of patterns of behaviour and knowledge which people have learned or created. Every perspective is then flipped, that is, it is problematised or reflected upon, from every possible angle, to uncover a multitude of possible explanation. The fieldwork continues with a refined focus, to illicit further dimension, and affirm or discount theorising.

These processes recognise the problems inherent in observation. Being observed naturally heightens participant’s self-perception, therefore the field-worker is in an ambiguous position. It may be one of power, through access to the naturalistic environment whilst, conversely, participants may only make known what they think the researcher wants to hear, or what they choose to pass on. Consequentially, various multiple forms of data, from various participants over time, add to the authenticity. They may also draw out contrasts that return the researcher to the field to uncover what is happening and why, or return the researcher to the data for ongoing analysis.

**Taken-for-grantedness**

The use of terms that refer to nuances, salient, intuitive, taken-for-granted and common knowledge, as used within this thesis, have been clearly articulated in the introduction. The implications of these forms of knowing, within an ethnographic inquiry, are now highlighted, as researching one’s own culture increases the potential of overlooking these forms of knowledge because everything is just so familiar (Lawler, 1991). The researcher must constantly ponder the authenticity of information, actively seeking multiple realities and comparative data, for in accepting reality it is inherent that no group is homogenous and people do not necessarily seek
cultural acceptance. Additionally, the researcher must accept denied access due to the methodological attribute of respect. A sense that something is missing in this situation, becomes part of the data and the discussion in the ethnography.

**Attributes of Ethnography**

The attributes inherent in descriptive ethnography were detailed by Barrett (1991), Hammersley and Atkinson (1983) and Spradley (1980), as the naturalistic situation, reflectivity and respect. These attributes are now expounded upon as they direct the research process, embedding a humanitarian position, avoiding notions of covert research to judge another. The following section therefore looks at the methodological notions of naturalism, reflexivity and respect and the meaning they give to an ethnography.

As the previous chapter *Situating the Self* has clearly acknowledged, the researchers, by virtue of their humanness, influence the substance, tone and focus of inquiry. Background, experiences, feelings and reflections of all the participants impact on the process and form an interwoven discourse within the text. As one listens with care, archives of knowledge, invariably, emerge. In accord with the methodological attributes and the humanistic underpinnings of the research, these must be accepted with respect. The ideologies of naturalism, reflectivity and respect, support the authenticity of the ethnography, for the participants inclusive of the ethnographer, at that point in time when the fieldwork took place.

**Naturalism**

Naturalism implies the value of the mundane, claiming that people and interactions are only understood in context, that is, in the naturalistic setting. Emic knowledge (the insider’s perspective) is gained from the subjects in the natural setting and is a way of knowing that only a participant can fully appreciate. Sensitivity and respectfulness are inherent in the research setting, to enable access to the meanings that guide behaviour. The language of participants is maintained as closely as possible and recorded, verbatim, to maintain the context and meaning of participants.

Understanding necessitates learning about the culture to avoid arbitrary perspectives being imposed. As Hammersley and Atkinson (1983, p.7) state,

> ... people interpret stimuli and these interpretations are continually under revisions as events unfold and shape actions. According to naturalism we must use an approach that gives access to the meanings that guide behaviour so we can come to interpret the world in the same way they do.
To assume the meaning of another’s language or their actions is to risk misinterpretation and to expose one’s self as the researcher to cultural ethnocentrism.

**Reflexivity**

The process of reflexivity is achieved through the continuum of data collection and analysis, describing differences and similarities, that leads to further questions and ongoing refinement of the research process. Reflexivity is more than re-reading one’s diary. It is a tool to encourage debate, to flipside and draw forth unexpected themes and finitely refocus the fieldwork. Reflection frees habitual ways of thinking and acting, in the process of becoming critically aware of our assumptions about the world (Hammersley & Atkinson, 1983; Barrett, 1991). As Boud, Keough and Walker, explain, “[i]t is an important human activity in which people recapture their experience, think about it, mull it over, and evaluate it” (1985, p.19).

Boud et al. (1985) draw on the writings of Kelly (1955) and Freire (1970) to highlight the value of individuality and context, cautioning the researcher not to assume another’s perspective, as events are given meaning by the person constructing the meaning. Perceptions are culturally induced hence, meanings can only be comprehended in their unique political and social contexts. Consequently, “… one must again and again return to the person before us” (Abbs, 1974, cited in Boud et al., 1985, p.23).

**Respect**

Whilst seeking to understand and learn from another culture, the third attribute of ethnographic inquiry, is respect. Methodologically, respect for participants is an overriding imperative (Hammersley & Atkinson, 1983; Spradley, 1980), because respect implies that any incident is critical by virtue of being important to the participant (Norman, Redfern, Tomalin & Oliver, 1992). Perry (1993) stresses the complex power/knowledge equations inherent within the process of ethnography and, therefore, argues that the researcher must believe that other people’s lives and stories are of value. Respect is implicit not only to the authenticity of access, but to the quality of access and, consequently, the authenticity of the ethnographic text (p.186).

The attribute of respect flows through the ethnographic process, encompassing reciprocity between the researcher and participants. Respect asserts the research ought to emanate from the needs of the participants so they are not used by the
researcher. Therefore, an ethnography cannot be covert: the researcher/fieldworker can not pretend to be other than who they are, in order to maintain the authenticity of the information and to maintain an ethical commitment to the participants, based in the synergism of the research and the principle of respect as explored above (Barrett, 1991; Hammersley & Atkinson, 1983; Perry, 1993; Spradley, 1980).

**Truth and authenticity**

Validity and repeatability are dominant issues for research per se, but an ethnography does not suggest it isrepeatable. Anthropology and therefore ethnographic processes search for understanding, with notions of truth and authenticity.

The search for truth and authenticity begins with the researcher situating themselves and declaring their prior knowledge, values and biases. The researcher then participates over a prolonged time in the naturalistic setting, employing the attributes of reflexivity and respect, to reduce reactivity to the researcher’s presence, whilst coming to understand the life patterns of other people. The search for truth and authenticity are woven throughout the ethics of access and participation for the researcher; and the attributes of reciprocity, naturalism and respect underlie the researcher’s presence, data collection and analysis, that is further detailed in the following chapter, *Being in the Field*.

In summary, the routine methods that assist such qualitative inquiry to be strong, with accuracy and intent, include:

- being true to the attributes of the ethnography, of naturalism, reflectivity and respect (Hammersley & Atkinson, 1983);
- the use of multiple forms of data, various perspectives on the data, and flipsiding, to ensure many perspectives and comparisons of a single phenomena (Spradley, 1980); and
- the participant-researcher relationship must be grounded in mutual respect (Connors, 1988).

Authenticity is embedded in naturalism, respect and reflexion, and, as Murphy (1989) explains, authentic understanding is revealed from constant dialogue between discovery and verification. There is however no claim to being repeatable, but strong claims to authenticity and truthfulness “... rul[ing] out absolutism and offer[ing] cross validation as well as recognising different interpretations from different perspective’s” (Sevigny, 1981, p.73). As interpretive research specific to a given time and place, cultural generalisations are never final, remaining open as a working document for further study.
An Overview: Ethnographic process as a framework of inquiry

Since nursing is grounded in the interaction between nurses and patients, the ethnography viewed a district nursing service and a group of patients, collectively, to study the culture of nursing from patients’ perspectives, in the context of being nursed in the home in a rural area. The experiences and feelings about being a patient, and the meanings people attached to these experiences, were sought and linked to receiving nursing, viewing the relationship between nurses and patients as the fundamental reality of practice.

The following was the proposed shape of the research process:

- **The method** was ethnographic processes using *Participant Observation* by Spradley (1980) as a framework to direct the research. As a novice to cultural studies, I found that Spradley provided a step by step approach that was supported and expanded upon in associated literature. This provided a framework that sought, and maintained, a strong and meaningful respect for the subjective experiences of participants. Reciprocity and respect is maintained through the entire research process, and is specifically exemplified in the chapters *The Nursing Narratives* and *The Patients’ Voices* to give uncompromised voices to nurses, nursing and patients.

- **The setting** was established through a rural district nursing service which was part of the nursing division of a base hospital in a rural area. The ethnography viewed a district nursing service as a group of nurses, patients and significant others, in conjunction with the social, economic and political environment of the community.

- **The ethics** of ethnography were grounded in the honesty of the researcher to naturalism, reflexivity and respect for all participants as equal. I found this essential to achieve positive, privileged access to people’s very private interactions. These positions that were also emotionally comfortable as I was a nurse and a patient as well as the researcher. Access to potential participants and the research process are clarified in ethic application documents which included consent forms, a semi-structured interview format and plain language statement which are presented in Appendix 1, 2 and 3, respectively. These documents were submitted and subsequently approved by the Institutional and University Ethics Committees. Further discussion about the ethics of doing ethnography is entwined with access and is detailed in the following chapter, *Being in the Field*. 
• **The fieldwork** was planned over three months. During this time I would accompany the district nurses as a non-participant observer on their rounds. Access was tied to the nurses, as gatekeepers as a negotiated mode in order to achieve positive access. (Positive access implies an attitude of participating that all participants truly felt at ease with.) The fieldwork proved to be an intense time, during which I was subject to a steep learning curve. I consistently worked back and forth through the various stages of fieldwork, watching, listening, reading and questioning; then recording data and reflections, and refining the direction of the research to uncover a deeper layer of understanding about what I was seeing and hearing. It also revealed many methodological challenges, such as balancing friend and foe (Coe, 1991), a focus of positive access, participants as people rather than informants, multiple forms of data and being neutral in my own culture.

• **Interviews** are technically part of the fieldwork. Nurses were interviewed informally, which simply implied constant general conversations, questions and discussions. Patients were observed for a minimum four visits with the nurses providing acts of nursing, then I would make arrangements to visit and interview them privately. I allowed ten minutes for introductions and explanations, then the micro-recorder was turned on and I sought answers to the questions according to the interview format. Ten to twenty minutes were allowed for this phase and then the recorder was switched off and people were thanked for their time and contribution, and reassured of confidentiality.

The interview format (Appendix 3) was adapted from Norman, Redfern, Tomalin and Oliver (1992) and Spradley (1980). The patient interviews varied. They ranged from informal, general conversation in patients’ homes, to private structured interviews with patients and carers that were predetermined in accord with the outline submitted for ethics approval (see Appendix 3). The first section aimed to describe the culture of district nursing from the patient’s perspective (adapted from Spradley 1980, pp.122-129). The second section aimed to elicit information about the process of nursing provided by the district nurses (adapted from Norman et al., 1992), using Flanagan’s critical incident technique. Both contained unstructured questions and contrast questions to describe the culture, seeking both the similarities and contrasts, and positive and negative aspects. The nurse interviews were all informal discussions, while they provided nursing, as we travelled between patients homes, or during tea breaks.
• **Analysis** occurred with an ongoing return to the data in a continuous cycle. The numerous phases of analysis provide similarities and contrasts, which led to some quite complex patterns emerging, whilst other areas incessantly returned me to the data with new questions (see Appendix 4). The following few years were, in reflection, a stage of ongoing analysis, as internalised distancing occurs until the data takes on an objective dimension and the analytic process begins again. Finally, the writing of an ethnographic text grew from the initial and ongoing writings based in fieldwork and cultural artefacts. It was difficult giving these notes academic form since it required being true to the experience whilst simultaneously being descriptive, analytical and true to ethnographic principles. The greatest challenge was in seeing through my own nursing culture despite my explicit initiation for this research through the experience of being converted to a patient.

**Summary**

This chapter has outlined the distinct research methodology of anthropology and the framework for inquiry which is an ethnographic process following the research sequence outlined by James Spradley (1980). The aim is to understand the mundane reality of nursing practice, specifically focusing on the cultural norms which give meaning to patients’ perspectives.

The methodological chapter seeks to make it clear that the ethnography is an evolving process for the researcher, with others who participate, unique to the time, place and circumstances where it occurred, so that meaning begins on a situational level. The anthropologist collects first hand information (in the field), to capture social and cultural characteristics guided by the defining principle of understanding and the underpinning attributes of equality, respect, and reflexivity in the naturalistic setting. Ethnographic language is explored and defined as used within this thesis, then an overview of the planned research process is detailed. This form of ethnography is blatantly interpretive with the ethnographer bringing personal socialisation and preconceptions, as do the participants and the reader (Spradley, 1980).

In 1951, the sociologist Professor Everett Hughes noted that, nursing, more than most occupations, is a complex bundle of tasks held together by the social role, as
the way tasks are performed always impacts on another person. Given this, he explains that the techniques of nursing ought never be studied apart from the persons, as the study of nursing is a study of a social drama; but as he went on to say,

[i]t takes courage to study one’s own work, just as it does to take a good hard look at anything which is dear to one and which one is proud (Hughes, 1951, p.294).
Participant observation is a marvellous technique. It provides a ‘feel’ for the subject: a comprehension of the subtleties of processes - of their contradictions and paradoxes ... [The intimacy with the phenomena being studied enhances the possibility of the researcher uncovering] ... tensions, conflicts and networks of influence and power, that interviewing will never uncover (Dempsey, 1990, p.9).

Being in the Field now draws on anthropology and ethnographic process, detailed in the previous chapter, as I now enter the field as a non-participant observer. It is written in the first person, relevant to the time when the fieldwork was undertaken, to describe the broad cultural landscape, inclusive of the environment, actors and interactions. The process of researching and recording information is structural, descriptive, intuitive and reflective thought, which is written into this discussion from the experience of negotiating access, being in the field, and the personal experiences and dilemmas of researching one’s own culture. Being in the Field is about the experience of undertaking the ethnographic process to seek an anthropological perspective about the culture of nursing.

Introducing the Study

Rural district nursing was a unique setting in which to undertake an ethnography of nursing. The home setting, as the place where nursing occurs, enabled observation of nursing in a naturalistic environment over an extended period of time. Patients who receive district nursing tend to require nursing over time, as a consequence of the underlying reason for nursing, such as the permanency of their illness, health care deficits (Orem, 1985), degenerative conditions, or the aging process. The home, as a patient’s naturalistic environment, therefore enhanced the reality of the observations, lessening (although not totally erasing) the expectation that nurses and patients will behave according to institutional rules.
The ethnographic record begins as I enter the culture of district nursing in a rural area of Victoria, Australia, to undertake fieldwork as a non-participant observer for the ensuing three months.

The Broad Cultural Landscape

The centre where the research took place is referred to as rural, as the language of the participants. In this community every individual whom I asked, regarded this regional centre as ‘rural’. Additionally, ‘rurality’ is the folk term used to capture the essence of living in a rural area, such as small isolated communities and vast, sparse distances. Davis and Doers (1993) point out that rural is a relative perception. Government criteria is based on various factors such as population density, services available and travel time. In contrast, personal experience, as a rural dweller and health care worker, has led me to know that people who live in non-urban areas include issues such as the quality of the roads, the expense, the availability of transport, sheer isolation and hence the degree of difficulty in accessing basic health services.

Rurality and the research

This is not my home town but the way people live, their sense of community and the politics which direct the provision of health care services, is very familiar. My teenage years and general nurse training were undertaken in a major city, but I returned to rurality. For the following twenty years I worked in rural hospitals, district nursing services, family planning clinics and as an occupation health nurse, whilst also being a member of a rural community. As a rural dweller and an integrated part of a similar community, this gives me a level of knowing and insight which enables me to be privy to an insider’s perspective of rural life.

By virtue of living in a rural town, patients and nurses are members of a common community with individual social roles, values, personalities, and a personal history in the community. Who each person is enters each nurse-patient interaction, distinguishing how one person will see another, and how they, in turn, are perceived. As part of a community, patients and nurses are frequently connected through aspects of education, work, sports, whilst they may also be socially and/or genetically related, and all these issues are reflected in nurse-patient relationships.

Every community is unique, yet common threads evoke the essence of rurality. Vast distances, isolation and an environment of extremes, result in a sense of communal inter-dependence. In rural centres, such as this, the local town is a regional centre for
education, business, industry, transport and health, servicing vast surrounding areas of country. This particular rural centre demonstrates diversity, from industrial and commercial estates, to a major rural city, small towns and isolated rural communities that are predominantly surrounded by farmed land. The rural towns are self-sufficient to meet immediate daily needs of the community, whilst distant metropolitan areas provide a central hub for major resources.

**Rurality and health**

Health resources are abundant in densely populated cities, whilst the isolating nature of distance and sparse populations over vast area, impacts on the availability of health services in rural areas. Specialist medical doctors, major medical services, paramedical and other specialist areas are all located in metropolitan cities. Inevitably too, even support groups tend to be in the cities, with tenuous outreach services to rural towns. In a rural town there may be a community health centre or a base hospital with an outreach program, such as a district nursing service. Subsequently, to access other than basic health services, it is accepted that people who live in rural areas must find a mode of transport and travel long distances. Roads and a tenuous public transport system are regarded by the broader society as an adequate link between rural towns and the centralised metropolitan cities. For example, in the area where this research was conducted, it was three to four hours travel (one way) to the metropolitan city, by road, which is the quickest link if one has a car, a license, and is well enough to drive.

The themes of distance and accessibility to appropriate health care are predominate issues that are specifically related to rurality (Malko, 1992). District nursing, for example, is disadvantaged by funding models which address direct nursing time to provide a given service, but fail to deal with the cost of travel time to patient’s homes.

**District nursing in rural towns**

Dempsey’s ethnography entitled *Smalltown* (1992) about life in a rural town, helped me see through the glorified sense of caring communities who ensure their own are cared for, which is the dominant public image that I am accustomed to in rural communities. In contrast, *Smalltown* provided insight, through my taken-for-grantedness, about the lives of the frail elderly and those with poor health or disabilities. Dempsey’s research, revealed that rather than being cared for by their community, many of these people spent most of their time alone. They watched television alone, ate alone and lost touch with friends and acquaintances,
progressively becoming marginalised from the rest of the community. Those with close family and siblings in the town only had limited contact with them, whilst, in addition, it was uncommon for family or siblings to take on the responsibility of meeting a person’s needs to enable them to remain at home (p.54-90).

As in Smalltown, the fieldwork illustrated the value the community placed on district nursing. District nurses who visit the home bring in the outside world as they talk and interact, regularly providing for people’s basic physical and emotional needs. They are very important to patients who choose home nursing and for those who can only access nursing through home services. District nurses also meet the needs of families and friends, whom Dempsey found were reluctant or unable to provide for their relatives, especially with intimate bodily care. They trust nurses will meet any medical needs, mediate with the medical profession, and provide physical and emotional care.

As one carer explained during the fieldwork;

If I’ve got any worries or anything I want to ask, she’s always terrific, you know, to sort of help me and suggest ... I couldn’t manage without them [the district nurses] I would have to put her in a home, there’s no doubt about it.

District nurses form a subgroup of nurses per se, practising on a very personal level, where nursing takes place in the community, behind closed doors in people’s homes. In generalising about rural district nursing, the nurses and patients have a unique and special interaction. The community are grateful for the nursing service as medical assistance is more limited and difficult to access for rural people, due to an aging population, distances between services and a shortage of health practitioners in rural areas. Consequently, the role of nurses who visit the home is highly valued. The nurses meet patients’ normative needs, are a source of knowledge and support, and a mode of entry to health care services.

Nursing in a rural area offers the nurse unique opportunities. In rural areas of Australia a good nurse is regarded with a particular social standing and respect aligned to the medical profession. Additionally, they have the opportunity to come to know their patients’ personalities, values, lifestyles and interests; to achieve a personal satisfaction from nursing patients as individuals in their community. On the other side of the equation is the lack of anonymity. They are never regarded as being off duty due to their visibility, accessibility and integration as a community member.
Local demographics of the district nursing service

Finally, in setting the cultural landscape, the initial fieldwork sought a broad in-depth picture of the regional medical service, as it is within this framework that nursing services were available to the community. As is the case in most rural centres, there is a base hospital in the main town, providing a range of medical, paramedical and nursing services, with smaller hospitals in the outer lying towns. In this instance, the base hospital served as a physical and administrative base for the district nurses, who provide nursing to people in their homes. Figure 4 now illustrates the structure of the service provision of the district nursing service from the base hospital.

![Diagram](image)

The shire run = approx. 20 Km to the next boundary

Figure 4: Structure of the district nursing service

The area serviced radiates outwards, covering approximately a twenty kilometre radius from the base hospital located in the rural city. The city is divided into five geographical divisions (ABCDE) designed to limit the amount of travelling between patients’ homes, decreasing unproductive nursing time. During the day shift, from 8 am to 4 pm, commonly referred to as ‘the am shift’, each nurse had her designated patients in one area, in a close geographic location such as adjacent streets, so that, in general, there were only a few minutes between leaving the home of one patient and arriving at the home of another. The outlying area was referred to as the ‘shire run’, reflecting prior local government structure where there was a central town, with the surrounding area known as the shire. The shire run is undertaken by the ‘pm nurse’ each afternoon, and again, those who live in a similar geographical area will be visited on the same day.
Information was also sought to enable an appreciation of the nursing services, such as the basic mode of functioning, structure, and purpose. An overview of the district nursing service therefore included broad categories, such as the service philosophy, various statistics, number of staff, work patterns, types of funding and routine procedures that shaped practice. The process of accessing this type of information required unrestricted access to daily work actions and interactions, and to the range of documents such as patient notes, annual reports, information about funding and directions and even work books. As a nurse who already was familiar with and respected the work of nursing, this was extremely interesting; and being a nurse legally sanctioned my access.

Ten registered nurses were employed by the hospital to work in district nursing on a dedicated basis, thus collectively forming the district nursing service. The service operates from 8 am to 9.30 pm, seven days per week, and provides a twenty-four hour on-call service for palliative care patients. The nurses are rostered to cover morning, afternoon, weekend shifts and are on-call overnight. In general, six nurses were rostered on Mondays, five on other week days, one on the afternoon shift, commonly referred to as ‘the pm shift’. On Saturday and Sunday two work the am shift and one the pm shift.

The am shift commences at 8 am, to be completed, if possible, by 4:30 pm. The pm shift commences at 1 pm and is due to finish at 9.30 pm. The am nurses cover the town in their allocated geographical areas whilst the pm nurse covers the shire (the surrounding 20 kilometre radius) from approximately 1 pm till 4 pm. The pm nurse then visits the patients listed for the afternoon, across all areas of the town, covering all the geographic divisions, until the work is done. The district nurses’ phone was connected to the hospital switchboard so the hospital administration could answer calls from between 9.00 pm until the nurses returned at 8.00 am. If the hospital administration deemed it necessary, the district nurse on-call for night duty would be called out.

The nurses are designated as the primary nurse in a geographical area (such as ABCDE) on a three month rotational basis, and one nurse is designated as the ‘reliever’ (the folk term). The task of the relieving nurse was to carry a minor patient workload, whilst assisting all the nurses, both on the am shift and on the early part of the pm shift through the shire run, with ‘double’ patients (which means two nurses were required to provide for the needs of a particular patient). The relieving nurse also covered the primary nurses’ patients when she was rostered on pm and weekend shifts. Therefore, although the ideology of primary nursing was maintained to a
substantive degree, as a consequence of the rostering system, nurses were not always in their primary area. In addition, primary nursing was not a reality when patients were moved between the nurses daily caseload lists, to even out the workload and, sometimes, to accommodate personalities.

In this district nursing service, resources were managed as ‘units of care’. Each case (patient) was measured by the time taken to provide ‘normative needs’ (Bradshaw, 1972), which was then calculated to provide a ‘workload’, that is the time taken to provide nursing for each individual patient, referred to as ‘units of care’. The nurses explained that the aim is to reflect nursing provided rather than numbers of patients visited. Ten minutes equals one unit of care: if it took twenty minutes at a patient’s home to provide normative nursing needs, this case equals two units of care. Each nurse was allocated between 32-34 units of care or workload of direct nursing per shift, which converted to 5.6 direct hours of nursing. On average, approximately forty hours of direct nursing care is provided per day, during week days, and sixteen to seventeen hours per day on Saturday and Sunday.

The term ‘caseload’ refers to one patient visit as a case. This has been used as a measure of nursing services provided by this service in the past and still remains in some documentation, such as the Annual Report. The report, for example, states that this District Nursing Service had an increasing caseload, thus an increased number of patient visits had been performed that year. However, this provides no insight into the amount of work performed, either physically or emotionally or in non-patient duties such as bookkeeping, documentation and liaison. Primary information was to be found in the nursing services work book, where patients are listed and workloads allocated on a daily basis throughout the year; this indicated a fluctuating workload, but one that is increasing per nurse, per shift, over time (anonymous annual reports, nursing work books and common artefacts of nursing practice).

These figures capture the structure and time frames for an average day, but as the following chapter, The Nursing Narrative, illustrates, a nurse’s day rarely follows straight forward routine. In addition to direct patient care, nurses do assessments, admissions, book work, accounting and liaison; as well as the unaccounted meeting of needs after work, professional development and update programs.

**The pathway of access**

The pathway of access to participants and the culture being studied is now detailed as part of the research process. Exploration of seeking and gaining access reveals a great deal about the intricacies and ongoing nature of negotiating access; about the
tenacity yet the intrinsic value of reciprocity and respect between myself, participants and the host institution; and a great deal about the organisational structure and hierarchical nature of health care institutions.

**Negotiating access**

Ethnographic fieldwork began with my approach to the Director of Nursing of the hospital. This was followed by a further meeting with the Director of Nursing and the nurse educator, who organised a subsequent meeting with the district nurses. These official meetings provided an opportunity for me to explain the intent and structure of the research, and to gauge the interest of the institution and of individual nurses who worked in the district nursing unit. Reciprocally, these meetings were an opportunity for the nursing administration to assess me as a potential researcher in their organisation and to assess, their perceived value, of my proposed research.

One formal meeting and a series of informal meetings with the nurses followed. We discussed the research proposal, drawing on the nurses’ insider knowledge to elicit their suggestions in designing the initial fieldwork. During this time I moved from soliciting support to discussing an official proposal and, finally into the role of a casual visitor for afternoon tea, talking, listening and being there, without imposing my presence. These visits lay the foundations underpinning the ethnographic process, paving the way for access through acceptance, whilst balancing the imbued ideologies of respect, reciprocity and naturalism. The process was time consuming, yet these informal visits were essential preliminaries and mark the beginning of the fieldwork.

Being in the field helped me gain an appreciation of the broad sociological and cultural context of the environment, the participants and their actions. The research therefore commenced at this early point, through the processes of the Ethnographic Research Cycle (Spradley, 1980, p.29), the scope of the research project from broad to selective observations (Spradley, 1980, p.34), and the developmental research sequence (Spradley, 1980, p.103). Subsequently, the many forms of data collection commenced, beginning fieldnotes with notations about the introductory attitudes, demeanours, the official pathways to participants and even the physical nature of buildings and the settings. As the notes progress, they reveal various levels of the physical and socially constructed layers of the environment, the interrelatedness of one area to another, people to other people, then areas to people, people to actions and so on.
Being with the nurses informally and being a nurse and patient myself enhanced my appreciation of access. Access implies the legal affirmation to enter the field, yet I came to appreciate a unique dimension, which I have referred to, earlier in this thesis, as positive access. Positive access encompasses acceptance and rapport, merging as part of the group, and the privilege of being given access to the very private world of others. Positive access was highly valued because the greater the acceptance, the less filtered my access and subsequent information. Acceptance also eased the pathway of negotiating official access, which is reliant on participants appreciating the intent of the research and the researcher. Access was always a tenuous issue, as the nurses, the service, and the institution, each control pathways of access that could be terminated at any time. An informal, supportive disposition was therefore an underlying reason why this particular district nursing service was appropriate.

**Ethical access**

As previously noted in the outline of the research process, university and hospital ethics documents were submitted to the respective ethics committees using the same consent forms, semi-structured interview format and plain language statements, worded according to fixed hospital and university criteria. The research process and access to potential participants was fixed to ethical considerations which were clarified in the ethics application documents that required official approval and clearance before the research could progress to the fieldwork.

Whilst awaiting ethics clearance I patiently worked my way through the bureaucratic pathways that gatekeep hospital and nursing culture. My reflections at this time are reminiscent about the opportunity to be inquisitive, become familiar, and personalise my presence, whilst these interactions served a secondary purpose of enhancing notions of trust and acceptance. Additionally, there was time to reflect upon and refine the fieldwork: planning with - rather than imposing a plan on - the nursing service. Plain language documents were refined to 14 point print as most of the patients were elderly. The logistics were organised, such as tape recorders, tapes, forms for fieldwork and a data base on computer file, so all was ready for the fieldwork when ethics approval was received.

In reflection, this time contributed to the research process as the nurses and I become people to each other, rather than researcher/participants. Finally, when approval was received from both the Hospital and University Ethics Committees, I was ready to merge from a nurse researcher seeking support for research, in to a non-participant observer in the field, and eager to move through the layers of the research. The charge nurse had been notified by the medical administrator, nevertheless, in
soliciting support and a positive disposition, I personalised confirmation, meeting with the charge nurse, then the nurses, to inform them first hand that the fieldwork could officially commence.

**Accessing Participants**

The process of eliciting participants is now elaborated on, as it conveys much about the structure of the service, issues I faced as a researcher, ethical issues the nurses faced, and a great deal about everyday issues for nurses and patients. Twenty patients commenced, four withdrew or were not completed. I participated in morning, afternoon and weekend shifts, during twenty-four individual shifts, for one hundred hours, over three months. I would meet the district nurses at the base, travel with them, entering participants homes where I would directly observe the nursing provided and the patient-nurse interaction. Each patient was visited and the patient-nurse interaction observed on at least four occasions, then I arranged to interview each patient privately. In addition, I spent time during tea breaks and organisational time at the nurses’ base reading, watching, listening and asking questions.

From one perspective, the institution, the nursing service and the nurses had all consented and formally accepted the ethics approval, plain language statements and consent forms; yet, conversely, my being in patients’ homes would inevitably impact on the nurses’ and their patients. The nurses requested a further assurance that patients would not be subject to any distress, as this would negatively affect the provision of nursing and patient outcomes. As one nurse patiently explained, 99% of the patients were elderly, (that is, over 65 years of age) and elderly patients are often anxious about strangers in their home. Just as important were issues of maintaining and respecting the intimate nature of nurse-patient relationships, as well as tactfulness, confidentiality, anonymity and legal issues.

This discussion alerted me to paternalistic notions, however, as a nurse researcher, I appreciated the protective nature of the nursing relationship, in particular the taken-for-granted and silenced ways in which nurses protect private bodies (Lawler, 1991) and mediate between the patient and the outside world (Littlewood, 1991). As a patient, I valued the role of nurses in shielding patients from preying eyes, as no one (but an insider in similar circumstances) really appreciates the invasive experience of being observed whist being nursed. Additionally, these patients were already vulnerable because it was public knowledge when someone lived alone and if they were unwell or fragile, which in turn became very public when the nurses visit.
I wondered if I, too, was being paternalistic but, as a nurse and as a patient, I also would have sought an assurance and a level of control over confidentiality and access to very private information; hence, as the researcher and an insider, I respected and accepted the nurses as ‘gatekeepers’. In addition to my personal position where respect for all participants was a moral imperative, this was also an attribute of ethnography, therefore it was a methodological imperative. The logistics of protecting patients and the role of nurses as gatekeepers is now explained.

**Nursing and gatekeeping**

Accepting the role of the nurses as gatekeepers also meant I would accept their prior knowledge, understanding and judgements as to the patients I would approach. In effect, the nurses controlled my access to the patients. All observations of nursing care were to be undertaken with the nurse present and I would only access patients for private interviews if the nurse and the patient both agreed. The nurses maintained control and a protective role for patients and I respected their judgement. This step aimed to decrease the vulnerability felt by patients and convey respect for patients’ privacy, whilst also assisting to ensure consent was valid. The district nurse was the gatekeeper and, if they felt at any time that my presence was inappropriate, I would leave.

The nurse’s professional judgement dictated who I would approach in the first instance. I would enter the homes with the nurses, who then introduced me to the patients, explaining that I was a nurse doing some research about the nursing service and its patients. I then explained the purpose of the research and the anticipated involvement of patient’s. A plain language statement was left with potential participants so they had time to re-read and consider this, whilst some had their family read it and took their advice. After a few days I would return with the nurse on duty, to see if they remembered who I was and the outline of the research, and to assure myself and the nurses of the level of competence, and thus of informed consent. Again, I called on the nurse’s professional judgement as we made a joint assessment of competency. When (if) a patient agreed to participate, the plain language statement was left with the participant as a reference document. The consent form was recorded and filed in a locked cupboard.

To maintain a patient’s anonymity throughout the research process, each participant was originally given a code in the research documentation and various fieldnotes and, later, codes were assigned pseudonyms. Finally, the patients were grouped into ‘types of patients’ and collectively given pseudonyms so that patient names within
the actual text and the accompanying narrative is a compilation. This was particularly important to maintain participants’ anonymity; the ethics documents had stated that no person would be identifiable as the patient information would only be released in the totality of the report.

About 50% of the patients whom I saw, who were judged by the nurses as potential participants, went on to consent to being part of the research. Two patients explained that they did not mind being observed, but were apprehensive of signing documents and being interviewed. One patient immediately changed the subject and I accepted this as a preference not to pursue this issue further. Some were simply not interested or changed their mind by the following day. One patient was deleted from the study as, after having signed consent, it was expressed by two nurses that they assessed this patient as confused. The patient lived alone and this, combined with possible confusion, presented a potential dilemma of consent and invasion of privacy. Two patients withdrew and one was not completed as, after my second visit, this person was no longer seen by the nurses; nor was nursing recommenced during the time of the study. Twenty patient participants commenced and sixteen completed.

Patients who were on the district nursing run but whom I never visited, and therefore did not form any part of the descriptive research, included those the nurses described as timid, not liking change, confused or psychotic (related to medical diagnosis and/or medications).

Nursing

The District Nursing Service has previously been described as part of the broad cultural landscape. The hospital was the controlling institution, as nurses were direct employees and the medical profession was the dominant social and professional body in the hospital structure. In addition, the hospital administration controlled nursing through funding allocations, hospital policies and hierarchical hospital management structures.

Nurses

The nurses were all women who had been hospital trained and had worked as nurses for between ten to twenty years. Nurses were division one registered nurses, referred to as general nurse, nurse, or ‘sister’ (as the accepted folk language). The ten nurses who collectively worked as district nurses all agreed, as individuals, to participate. This was fortunate, as ethnography involves constant observation and interpretation; including conversations during working hours, conversations at a professional level
about patients where information is classified as confidential, and general
observation of scenes. Ongoing negotiation of access assured the nurses that the
study was descriptive, with one aim being to provide an archival record about the
complexity of nursing.

The nurses, though apprehensive of an increasing workload, were willing to have me
tag along; so long as I collected the data, did not intrude on their time, did not affect
their patients, and accepted their judgements as to whom I saw.

The patients

Twenty patient participants were conveniently selected, albeit filtered through the
nurses as gatekeepers. Participants were elicited during the fieldwork, as I travelled
with the nurses. In seeking participants representative of the service, I considered the
geographic areas and social demographics and sought five participants from each
area. I then considered age, type of nursing and gender. Patient participants hence
included those admitted for technical procedures, basic nursing care and palliative
care. The twenty patient participants were existing patients with the exception of
one, who was a new admission during the fieldwork. Participants were
predominantly female, aging, and had chronic conditions for which they sought
various forms and levels of assistance, which was reflected in the patient profile of
the district nursing service.

Despite the categorisation of types of nursing, most patients required various
combinations of categories of care and were referred to as requiring basic nursing
care. It was rare that the nurses visited a patient and only performed a technical
procedure such as a wound dressing. Nor did the nurses consider nursing needs as
isolated actions that fitted into neat categories. Conversations with patients, when
asked what the nurses did, also presented a different perspective. Some explained
what the nurse did in physical terms, whilst others said the nurse dropped in to say
hello, to do a dressing, shower them, give them an injection.

Patients were referred by their general practitioner, either directly or through the
hospital, or by any concerned person, including self-referral. It was taken-for-
granted that if a person sought nursing assistance themselves, the community, or the
nurses, would take care of this and organise a medical referral, if the patient was
regarded as legitimate (a socially constructed value). People in rural communities
take care of their own (and subsequently themselves). A doctor’s referral legitimates
the patient’s needs, but also the act of nursing and therefore, the role of the nurses. In
contrast, patients rarely spoke about a medical diagnosis, prognosis, health status,
impairments, or ailments but they accepted the medical referral as access to nursing and, simply, as the norm; the way one accesses help to do with bodies, in our society.

The town boasted a number of medical clinics where the fourteen doctors, one of whom was a female, were based in group practice. The nurse occasionally needed to ring the doctor to liaise about a patient, though it was uncommon to actually speak to the doctor. Just as nurses gatekeep their patients, others, such as secretaries, are employed to gatekeep doctor’s time, similarly controlling who has access and when, protecting the doctor from interruptions. The secretaries take messages and, in the afternoon, when the nurses return to the base to liaise and do their documentation, they return the nurse’s call - or the doctor may ring in person. It depended on the nature of the contact, who the patient was, who the doctor was, and to a lesser extent, the professional and community status of the nurse.

**Being in the Field**

Discussion now returns to the fieldwork, where I spent the ensuing three months consumed as a non-participant observer. Fieldwork constantly imposed an exhausting learning curve, to appreciate and capture the simplicity of mundane reality, through a continuum of constant refining and refocussing; of negotiation of access, participation, observation, interviewing and analysis. The process was never-ending, as new questions arose and the cycle began again. During the fieldwork, over the ensuing months, I became submersed in the everyday lives of the district nurses and the patients; enculturated, existing in a state rather oblivious to my normal role and responsibilities with my family, friends and colleagues.

As the ethnographer, I was located in the field as an observer, involved and participating overtly and covertly in the everyday lives of the participants (the nurses, patients and significant others), as I sought to uncover the cultural knowledge that constructs and gives meaning to the experience of nursing. In similarity with the nurses, I wore a navy blue skirt and jumper, to blend in with the everyday images and normalise my presence in the environment but, in order to declare my difference, this was not the nurse’s uniform, and my individuality was further accentuated by the cervical collar I wore.

**Methodological Issues in the Field**

The experience of commencing fieldwork highlighted methodological issues, as they seemingly evolved and resolved themselves, therefore it is timely to pause and discuss these issues as they aid in contextualising the environment and my
relationship with the participants. The main issues were concerns of covert research to serve another goal, reciprocity, collegiality, and the tensions of walking the fine line as a researcher.

As the fieldwork commenced we all felt some scepticism, about the logistics of accessing a broad representative group of patients, spread over a broad area, within the given time frame. This was a real concern and when the nurses made some suggestions to overcome some of the issues, I agreed, appreciative of their local and taken-for-granted knowledge. Furthermore, in bringing these issues to the fore and suggesting solutions, the research had began to be collaborative, learning from the culture.

**Concern about covert research**

The nurses expressed two particular concerns about the research. Firstly, they were concerned about the descriptive nature of what I referred to as research. Secondly, they were concerned about why I was looking at their particular service. There was an underlying belief that research measures service provision in quantifiable figures, and there was concern, and perhaps fear, that the research had a silent agenda - to demonstrate their service was inefficient and needed restructuring.

To reassure the nurses I produced the ethics documents declaring the proposed use of the research and explained that the research was tied to this by law; but there was still a sense of vulnerability. I could assure anonymity but in reality (and rurality) we all knew the innate limitations. My credibility in reassuring the participants of my intent, was grounded in personal affinity, enhanced by the legitimacy that I was a nurse and had been a rural nurse in clinical ‘bed side’ practice. Until I was injured (a factor that also legitimated my defection from clinical practice to research and legitimated my non-physical observer stance) my practice was similar to theirs; the unseen generic nurse. The nature of this research carried through a similar theme, seeking to make public the value of the mundanity of bedside nursing. As such we had a personal affinity and mutual appreciation of nursing, grounded in ‘basic nursing care’, and emphasis on this alleviated their anxiety both in the initial instance and over the ensuing months.

In addition, as the research progressed I was able to demonstrate my observations. I maintained a running-working-document of fieldnotes, and offered the nurses the opportunity of viewing selected anonymous notes during handover. Retrospectively, this opportunity demonstrated the relationship between the research and everyday nursing practice, whilst decreasing concerns about covert research. Their concern
was not unrealistic as the economic and political environment at the time of the fieldwork, and of writing this thesis, is one of change without consulting practitioners or participants. It was therefore imperative to consistently reinforce the descriptive nature of the inquiry and to maintain a positive view of the research in order to sustain ongoing positive access and participation.

**Taken-for-granted knowing**

By participating in the culture under study, my awareness was raised to the various levels and forms of knowledge used in practice. In standing back, it became possible to see some of the everyday silent and taken-for-granted skills nurses assume. The nurses managed themselves (and, in effect, the district nursing service) in a laissez-faire manner, sharing out the workload, travelling miles each day, visiting numerous patients as dramas occurred and were resolved. For example, if a patient was unwell the nurses ensured that they were linked back to the medical system and their concerns and needs followed up. Tensions were mediated, lost medications found or replaced, patients’ needs met. Relatives, families and patients were contacted, consoled, supported and so on. What needed to be done was done and, despite the complexity of nursing people in their homes, the nurses’ shifts proceeded with an outward appearance of efficiency and organisation.

These were the taken-for-granted ways of practice that I had been abstractly aware of, as I too had done all this. It is everyday, common practice knowledge, that is certainly not to be found in nursing manuals or located in theories of practice. Even to nurses, it is not explicit knowledge. However, as I move to the patients perspective, the taken-for-granted ways of practice form a veil, a see-through, porous layer that covers the patient. The taken-for-grantedness of practice now, inadvertently, yet also in a seemingly predetermined manner, shapes the patient-nurse interaction, as do nurses manners, words, language, and actions.

**Reciprocity**

Methodologically, the previous chapter has noted the need for the research to be reciprocal where, ideally, the aim of the research and expressed needs of the participants would be synergistic. As the fieldwork began, many nurses and patients revealed an eagerness to participate, to reveal and make public what nursing is about. They expressed frustration as they felt nursing was undervalued, taken-for-granted and under funded. As a consequence of these concerns, those who participated, tended to see the research as a way of demonstrating how much nursing was provided with limited resources; or that the research could make public the inability
of nursing to meet patients’ needs because of resource restrictions. Overall, participation was seen as a legitimate means of making these issues public, without the normal risks of personal vulnerability.

This enabled the researcher-participant relationship to begin with respect for each other that was positively beneficial to access. I was a researcher, nurse and patient, who appreciated and shared their concerns; bringing these issues into public view was a valued outcome for us all, and as a consequence, the research was collaborative, which, in turn, eased the path way of access and resulted in positive participation from a reciprocal position.

I was relieved and grateful, for the supportive position and appreciative of the legitimacy conferred towards myself as the researcher and towards the research. There was an acknowledgement from the patients that, as a nurse, I was not a threat to the elderly who lived alone as they place unquestioning trust in home nurses. In addition, many patients expressed or made known their personal affinity towards me because I was a patient; I was accepted to varying degrees as ‘one of them’. Maintaining the ethnographic attribute of respect was effortless - the nurses practised what I wanted to do most and the patients were in a similar position to myself - respect is easy when there is a deep common bond. In turn, collaboration and reciprocity reinforce and strengthen the obligation of myself, as the researcher, to ensure that participants’ concerns and the ethnographic text are made public and disseminated as broadly as possible.

Fieldwork

From the researcher’s perspective, as non-participant observer in patients’ homes, it took time to feel at ease and believe the scene had reverted to the normal routine. This was not unexpected. It is consistently discussed in the methodological literature (such as Fetterman, 1989; Hammersley & Atkinson, 1983; Hughes, 1991; Spradley, 1980) as a significant rationale supporting a prolonged period of being in the culture under study. It was my pleasure to listen and talk inquiringly with ease and it was my constant challenge to absorb not only the answers and stories but to appreciate the meaning they conveyed and refine my questions to seek further knowledge and understanding. By virtue of one’s presence, it is normal social practice to participate and be included in conversations and I soon learnt that the environment, the participants and myself, were all more at ease if I joined conversations. Concurrently I needed to be aware of my participation and use these conversations to reflect back participants feelings, or to allow them to feel I was listening if they wished to expand.
Participation in the field over an extended length of time, and observing episodes of
nursing at random, slowly drew attention away from my presence so that, in time, I
was accepted as ‘part of the routine’.

As I accompanied the nurses, the fieldnotes which had begun with my first approach
to the institution, continued; consistently taking on a new focus. Initially they were
descriptive whilst over time, fieldnotes and reflections become a complex integration
of descriptions, conversations, and reflection on actions and interactions. This is
described by Spradley (1980) as the Developmental Research Sequence, which
refocusses the research inwards; also serving to confirm, or cause me to question,
any underlying assumptions I was forming. Data was inclusive of organisational
structure, process and policies, unit process and policies, observations, informal
discussions within the patients’ homes; and also general informal discussions
inclusive of all participants.

During the fieldwork I felt that writing fieldnotes with others (such as the nurses)
present would disturb any sense of normality, therefore brief notes were taken as
soon as practical. In the main, however, as I travelled with a nurse each day and only
a few of the patients she saw were participants, I would wait in the car. This
provided an ideal time to expand on the fieldnotes, usually within a few minutes
following an observation. Later, after the shift was completed, I would further
expand the fieldnotes, seeking to capture the essence of what was happening and to
reflect upon this. As the fieldwork continued, observations were consistently refined
as questions were answered and new ones became apparent.

Entwined with the ongoing cyclic nature of the research were the interviews -
language indicative of a formal process but, in reality, merely implying ongoing
discussion. A diverse range of discussions at various levels of formality sought to
describe nursing from nurses’ and patients’ perspectives, to elicit information about
the process and experience of nursing, whilst seeking to maintain the individual
essence of experiences.

The patient interviews were staggered throughout the fieldwork phase, depending on
when the patient had become a participant and when observations were completed.
During the final visit with the nurses, I would organise a mutually convenient time
for the interview and reinforce that I would be alone. On arrival there was the
inevitable cup of tea, which I always accepted as an appreciation of participation and
reciprocity. Then, whilst we talked, I would outline the interview and when they felt
comfortable, turn the tape recorder on.
In general, most patients talked freely as they were accustomed to my presence. In addition, as previously noted, my dual personal situation conferred cultural legitimacy, which freed patients; it is acceptable to talk about the intimacy of nursing with nurses and other patients. After the first few interviews I relaxed. Soon, the questions became mere prompts in our conversation; but necessary ones, to keep us on track and to ensure that the same information was sought from all patients. These private interviews also provided an opportunity to finalise the research with each individual patient and as an informal debriefing.

All of the nursing interviews were informal ongoing discussions. Being integrated into nursing culture, and travelling with the district nurses, provided opportunities for general conversations, to listen to individual nurse’s opinions, to focus and re-focus conversations. At the base we talked, or I simply listened as the nurses talked, wrote their notes, apportioned tomorrow’s workload, and talked about their day and incidents. Every discussion was valuable. Some validated what I was wondering about, others gave me their felt experience which may have been quite different to what I thought I saw. Others questioned what I thought about ‘things’, and this was a dilemma. I would try to turn the question around, back to the recipient, to see what was underpinning their question, or to elicit their opinion.

Finally the data became saturated, as no new information or questions seemed to appear, and it was time to disengage from the fieldwork. I sensed that the nurses were relieved the fieldwork had finished and I accepted this as reasonable after three months, but I wished to convey my gratitude. I had sought a reciprocal learning environment for a research project and I was given positive access and a reciprocal relationship, all of which must have been invasive of their professional time and space. I therefore felt and remain indebted to those who participated.

It was their way, on special occasions, for someone to provide a treat for the tea break, so, in keeping with their culture, I hurried in with cake for afternoon tea, as the am and pm shifts crossed briefly for handover at the base. The phones began ringing, the door bell rang and it was time for us all to move on. The fieldwork phase was complete.

On an official level, I wrote to the ethics committees and informed them that the fieldwork was completed and thanked all the staff whom I’d had the pleasure to work alongside.
Methodological Reflections

The process and experience of being in the field have been explored, framed within the structure of nursing, as the means of accessing the culture.

An ongoing process

The fieldwork was completed on one level, but in reality it continues until the research is completed. The many forms of documentation focus on capturing the essence of nursing and being nursed; for reflection, as multiple forms of data, and to reveal a multiplicity of realities to enhance authenticity and avoid the risk of only accessing the dominant norm. Notations had therefore commenced when the concept of the research had first begun to take shape, when contact was made with the (potential) participating organisation. Fieldnotes were both written and audio tapes that were recorded at every opportunity. The first form was factual, describing what occurred through a sequence of events and conversations. In addition, I wrote about my feelings and thoughts and, over time, these became reflective. From these notes emerged further questions as I sought to refine and, consequently, to understand what was occurring.

Four years later, I continue to listen to the tapes of fieldnotes, interviews, and reflections; to listen and read media reports and journal articles which highlight various patient perspectives. I have found a strong body of text revealing the struggle of people who have an impairment or chronic ‘self-care deficit’, or who have been reliant on nursing. The common thread seems to be their vulnerability - physically, emotionally, and socially. Reflectivity leads to further questions and ongoing refinement of knowledge that is part of the hermeneutical spiral of knowledge acquisition (Markova, 1982). Time provides an unconstrained opportunity to gather and listen to cultural artefacts such as narratives that capture the essence of nursing from patients’ perspectives, and to consistently relook at the data as I become distanced. Distance enables the personal self to let go and see the data, building on prior knowing, but seeing through personal biases and taken-for-grantedness.

Reflecting on access

Hammersley and Atkinson (1983, p.56) explain, “[a]ccess is not simply a matter of physical presence ... or the granting of permission for research to be conducted ... especially in private cultures such as nursing”. Eliciting, maintaining and expanding on positive access was entwined with an appreciation of the formal and informal channels of those who consider themselves, or are considered by others, to have the
authority to grant or refuse access. Patients, as individuals, are vulnerable simply because they are patients. They need nurses and nursing, and nurses are frequently their mediation with the outside world (Littlewood, 1991). Consequently, regardless of access by ethical and institutional approval, nurses are gatekeepers to patients, therefore to logistically access this cultural group, I needed to accept nurses as gatekeepers; as those who legitimately control one’s access to patients (similar to gatekeeping as described by Hawker, 1985, in Gatekeeping: a traditional and contemporary function of the nurse).

Gatekeeping is not an unfamiliar term in ethnographic language. Methodological literature, such as Spradley (1980), notes that gatekeepers are an intrinsic part of the ethnography, as they are the researcher’s means of securing legitimate entry into another culture, and they enable an intimate level of access which is necessary for the ethnographer to learn what really occurs. In this research, gatekeeping was accepted and valued as I needed the nurses to negotiate my presence and legitimacy with patients and the broader institution. I also felt that it would be unethical to solicit patients in any other way.

Reflecting on being in the field

There was a constant fine line to balance being a non-participant observer in a profession I had practised for fifteen years; between assuming a work role as an observer rather than naturally assisting as a nurse; and the occasional conflict of being asked to assist, as staff and patients knew I was a nurse. There was also a fine line to balance the level of interactions I assumed. This wavered between some degree of social interaction and conversation (because I was in someone’s home and this is normal polite behaviour in our culture) and no social interaction at all, which would have radically altered the naturalistic setting. Concurrently, I needed to be part of interactions or I would have been excluded from the information and conversations which are a source of data. These factors had to be balanced to allow both patients and nurses to feel confident and comfortable with my presence, or access may have been silently restricted. In particular, patients needed to be comfortable with visual observation and confident to provide verbal information.

I could not become a friend, nor could I be unhelpful or pretend I was not there. I could not critique even if coerced to do so. The art of balancing one’s presence in fieldwork was typified by the need to be positive with all staff, never to critique or suggest; to be friendly so that I was part of the team, but to keep distanced to avoid in house politics. I was there as a researcher. Coe reminds the researcher that any


degree of comfort or wanting to be accepted could breed contempt, and subtle things may be missed (1991, p.330). In fact, the longer I participated, the greater the skill required to balance the nature and extent of participation, as one’s presence becomes accepted within the culture being studied.

Similarly, the notion of occupational access also alerts the ethnographer to this fine line in fieldwork. Occupational access as a nurse eased acceptance from the patients, nurses and the hospital and even conferred legitimacy. Coe (1991) suggests that, as the researcher, it is expected I would take ‘their side’ (the nurses) as, to some extent, access is given because you are one of them. In reflection, I was accepted into people’s homes as a nurse (even though my role was that of a researcher). I was safe - not a stranger, but a nurse. From the hospital’s position, I was an experienced nurse undertaking research and I was interested in their hospital, which was a fortunate and valuable position. Patients were (generally) accepting of me as I was a nurse, whilst acceptance was enhanced at a personal level as I obviously was a patient. I wore a cervical collar during most of the fieldwork and had physical limitations that I knew were obvious, from people’s comments.

Being a nurse, merging as one of them and respecting their practice, aided the research by providing the means to access intimate trusting nursing relationships. Acceptance and trust also enabled access to general conversations in the car, tea room, and during administrative time. It was a trust that, morally or methodologically, I would not breach. I do not perceive difficulty with the insights drawn from intimate and private conversations, but the challenge of the fieldwork, was to maintain anonymity whilst revealing the cultural nuances, as experienced, within context. At the same time, the trust, confidentiality and the ethical and moral imperative, along with the authenticity of the ethnographic text, had to be maintained.

**Summary**

*Being in the Field*, draws on the framework for the inquiry that was detailed in the previous chapter, to commence the ethnographic process as the initial level of description about the human constructed layer of culture in a rural district nursing service. It began with an exploration of the broad cultural landscape, detailing the pathways of access into the culture and the participants, and illuminating the experience of undertaking fieldwork and balancing oneself as the researcher in the field. Exploration of entry into the culture provides an in-depth base for the research to build upon, true to ethnographic attributes of naturalism, reflectivity and respect.
“They give you peace of mind - and if you’ve got that, you’ve got a lot”.

The Nursing Narrative is descriptive, anthological narration, describing the broad cultural domain of nursing, set within the daily routine of nursing, where nursing is the verb of action that refers to the nurse-patient interaction. Description about nursing therefore includes nurses’ and patients’ experience, but as this chapter is set within the shape of a nurse’s day, it is inevitable that the voice of nurses’ is dominant. The aim of this chapter is to bring to life and convey a picture about nursing to the public, but it also seeks to make clear nuances, silenced and taken for granted ways of the nurse-patient interaction and the many realities for all the participants in this cultural scene.

This chapter builds on the previous chapters which detailed the methodology, outlined the process of the inquiry and described the experience of undertaking fieldwork. A grand tour, surface investigation is refined to selective, then focused observations, to introduce the culture of nursing in its holistic complexity (Spradley, 1980). Narration is structured within the framework of nursing practice, describing the participants, activities, places, objects and relationships between these concepts within the domain of nursing. Events are given significance through exemplars from the fieldwork, through the fieldnotes and the ongoing process of reflectivity.

The ethnography is written as a narration, from my perspective as the researcher looking in; describing, then reflecting on, what I see, with a dialogue representative of the experience of both nurses and patients. As explained previously, all participants were grouped and a patient name and their story is representative of a compilation of particular kinds of patients to maintain participants’ anonymity. All quotes are extracts from the various forms of fieldnotes, unless they are otherwise referenced.
The Places Nurses Work

The district nursing centre was indicative of places nurses work in rural areas. Their base was an old, sparsely furnished house that was converted into an office, storage and staff room. This room is the centre of life for the district nursing service, humming with the whistle and steam of the kettle boiling, as it doubled as the staff room, and served many purposes. It was here that the ethnographic process began as I was introduced to this group of nurses; where we held ongoing discussions, came to know each other and where we met at the commencement of shifts throughout the fieldwork phase of the research.

The nurses rarely discussed the need for a comfy work environment, accepting the rugged vinyl chairs placed around the edge of the large room, the heater and the large wooden table that they shared for every function. The building was old, damp, cold and small, compared with the number of nurses (so highly organised with complex skills and knowledge) who gathered there for handovers, but it was their place with privacy and confidentiality held between its walls. The broad, bare street removed it from the incessant rush over at the hospital, but it was the linked with the hospital through answering machines, telephone calls, funding and policy directions. It was an annex - an extension where it was organised that nursing take place in people’s homes rather than in the large impersonal brick building. Here the nurses commenced the bleak mornings, returned for tea breaks and later for the writing up of nursing notes and legal documentation, apportioned each day’s workload, communicated and socialised. Here nursing stories echoed as nurses listened, laughed and learned from each other’s experiences, or pondered with remorse over someone’s suffering or diminishing being.

Registered nurses (RN’s) are employed by the hospital and form a distinct unit, known as the district nursing service, which provides nursing to patients in their home. The home is the physical environment in which each patient’s nursing needs will be met, yet the word reveals little about the nature of the environment. Patients’ homes were as diverse as the sociological groups and personalities of the population in this rural area. Each home was a unique entity that varied from grandeur to simple dwellings that were homely, comfortable, dirty and even dangerous. Homes were houses, units, or granny flats, whilst others were rooms in retirement villages or hostels. People lived alone, or with families, partners, friends or others; in buildings that echoed of the past, loneliness, contentment or resignation.
Home nursing is distinguished by the personal environment the nurse enters. It is a
distinction exemplified in rurality where lives are not private and little remains
confidential, rather, there is a generalised inference that people in the community
matter to each other. It will be common knowledge in a rural town when a person is
receiving district nursing and the nurses themselves may be neighbours, friends, or
relatives.

Nurses commence their shift, travelling from home to home, according to their
patient list, providing nursing, moving to the next home, to the next patient and so
on. Patients are the individual visits that make up the totality of a nurse’s day,
however, the nursing visit is unique and singular for patients and, as such, each
patient narration about their experience of being nursed differs fundamentally to the
nurses’ narrative. Patients, as a group, do not have a generalised day, and every
patient’s perspective and their interpretation of the patient-nurse interaction is unique
to the individual, their expectations, wants and needs. A patient’s day revolves
around the nurse coming. Their day begins in a similar manner to the nurses’, as
they both commence with routines, but a patient’s routines are constrained and
complicated by their dependence on nursing. Regardless of why a person receives
nursing, self-care deficits (Orem, 1985) impact on a person’s ability to function as
they choose. Often their life style has significantly altered from how it used to be.
Days are now entrenched in routines or, at the very least, dependent on the nurse
arriving.

The Morning Shift Commences

The morning shift commences. The setting and routines are idiosyncratic, being
repetitious and yet distinctly individual, throughout each day, every day of the year.
The nurses arrive at eight am; efficient and dependable. There is no clocking on or
off, and no one checks that the nurses arrive on time. It is expected that they are
honest and so the usual rules of employment do not figure in this equation. Even
their physical appearance could be described, by an outsider, as efficient. Dressed in
traditional navy blue and white, that are icons of nursing.

Their arrival transforms the old house as the quietly organised routines are set in
motion. Little is said at this early hour. The nurses rub their hands in an attempt to
defrost, as they greet each other, collect their allocated list of patients to be seen that
day, each patient’s care plan, and equipment such as dressing packs. They check the
book where the previous shift would have left any messages, unplanned visits, or
requests to admit new patients. Someone listens to the answering machine for calls
from patients, families or the hospital, which might have come in overnight. (Generally, ‘someone’ is the most senior nurse on duty at that time, which is the nurse who has worked in this unit for the longest period of time.)

Each nurse promptly departs in their designated car, the hospital emblem embossed on the side, announcing her moves to the community, obscuring any sense of anonymity for patients. These cars are organised with a set of basic equipment; a glucometer, blood pressure machine and the inevitable supply of linen and dressing materials to cover most eventualities. In a measured and given time, corresponding succinctly to the designated statistics of the allocated workload, the nurse arrives at the home of the first patient on her list.

**Access**

The nurse’s movements are quick and almost synchronised, from the years of doing this routine. The car halts at the home of the first patient as the nurse scans the nursing notes. The mode of access, patient peculiarities and nursing required are committed to memory from admission, it is only changes that need to be reviewed. Then the patient notes are closed from public view as they remain in the vehicle. Any equipment that may be needed is gathered, the mobile phone collected and the car locked. The nurse moves to the patient’s home, to the door they have negotiated access through, over time. The key is in the door, or the door is unlocked and the unspoken yet ritualistic negotiation of access becomes evident. The nurse knocks and moves in, or simply opens the door and calls out to the patient. She enters, calling out a greeting, identifying herself.

This is a negotiated entry; unique access, encapsulated in trust that patients reserve for nurses. The degree of confidence that is implied by such access, is unusual for the elderly, but so is the high regard they have for these nurses. They are women, they are nurses and therefore they are trustworthy; a position that remains unchanged regardless of other conflicting interpersonal issues. The social and occupational roles of women, an embedded division of labour based in gender and other social factors all overlapped, as patients expressed a preference for female nurses alongside a greater acceptance of women coming into their homes to perform the intimate tasks of nursing. Patients explained females are less of a threat (than males) even if they are strangers. Historically women were (and I would suggest still are) perceived as society’s carers and nurturers.
District patients are frequently elderly; they might wait in bed, in the bathroom, or simply save their energy for life. The nurse and patient chat as they meet, collect clothes and towels and move towards the bathroom. The nursing actions and assessment have begun in a totally informal manner, and so has the interpersonal relationship, the power balancing, and the meeting of nursing needs, that all occur so subtly.

The environment personalises the experience of nursing as nursing occurs in the private personal space of a patient’s home. Some patients viewed this as an intrusion; as risking their sense of self and dignity which is entwined with feelings of vulnerability. Lifestyles are exposed as a home is representative of, and gives others access to, the intimate manner in which a person and their family function; what possessions they have, the degree of opulence, cleanliness, types of relationships, personal habits, and so on. Similar to the trust placed in access and associated with the process of being nursed, a unique, unspoken agreement exists, as patients need nurses confidentiality.

The uniqueness of access begins with entry to the home, moving to the patient’s private lifestyle and finally to their personhood. Once nursing actions have been completed, access is closed with similar simplicity. Conversation will recommence days later when the nurse returns. The patient-nurse interaction is disjointed in regard to time, yet reflects familiarity, comfort, and continuity, exemplified in the manner in which conversations begin, cease and are resumed; belying refracted time.

**Nurses’ Routines**

Nursing commences in a routine manner, yet the ensuing discussions elicit information, forms relationships, and enable the nurse (and other nurses) to make ongoing assessments. The mornings are the busiest. Blood sugar levels and insulin injections are the initial visits, followed by procedures to be performed at regular intervals; then the nurse proceeds with her list of patients. There is much hurrying and patients are generally waiting for the nurse.

The nurses explained they understood different patient needs and concerns and tried to accommodate these. (Generally) the nurses regarded routines as beneficial, enabling them to organise their working day.

Patients repeatedly expressed a strong preference for regular, early visits or at the very least, a regular routine. Early showers enable patients to “...get on with their
Routines were described as “...maintaining some sense of normality”, whilst for some, early visits are significant as their sole means of getting out of bed so the day could begin. It’s often the way - some nursing routines have evolved to maintain a sense of normality. Other patients felt it was more important that the time the nurse arrived was regular, or that it was a familiar nurse with whom they felt comfortable. Overall, simply knowing that the nurse would come was the overriding value expressed by patients.

Routines are also valued by some patients, as they help them to make some sense of complex new lifestyles, through the support and simplicity which the nurses and the concept of routines, bring into the home. Patients know roughly when the nurses come and they organise their day around this. They know the nurse always comes and they are assured of assistance and, on the days the nurses visit, they relax from the rigours of self care. Likewise, routines enable patients to know what will occur and how the nurses go about certain activities, so it becomes familiar.

When nurses enter patients’ homes, routines simply occur. That is just how it is in nursing, which is, on reflection, a combination of rituals with taken-for-granted, tacit and intuitive knowledge, depending on each individual situation. Additionally, routines become rituals as a consequence of nurse training, the structure of nursing practice that is imposed by institutions or that nurses impose on themselves, arising from their socialisation and enculturation into practice. Likewise, the public image of nurses and nursing is repetitiously portrayed in the mass media, perpetuating society’s expectations, so patients come to expect and/or accept, ritualistic routines from nurses.

Practice is enshrined in routine. Nurses see patients in a predetermined order (the timing and mode of access having been negotiated over the years) and the way nursing occurs reflects historical and current day media imagery. Practice is also reinforced by an institutional and medical hierarchy that is dominated by a view that nursing is menial work which is of limited significance to people’s health. Rather, the nursing role is still perceived as aiding medical professionals to care for a patients’ environment, to ensure the cleanliness of patients’ bodies, and to monitor patients in their absence.

**Basic Nursing Care**

In reviewing nursing notes and listening to oral handovers about patient needs, the taken-for-granted knowledge of nursing becomes starkly obvious. What patients
needs are and what nurses do, is subsumed in simplistic language, repetitiously
phrased as ‘basic nursing care’. When nursing notes stated “basic nursing care”, the
reality of this revealed a continuum of nursing needed and provided that was
insidiously calculated. Factors that crept into this notion included the amount of time
the nurse could find in her daily workload, alongside subconscious considerations,
such as the social legitimacy of this patient; their illness and nursing needs as
assessed by the nurse, the nursing service or the treating doctor in accord with
society’s norms. In addition, patients are not an homogenous group and, therefore,
health needs are non-static and individualistic, hence the meeting of these revealed a
complexity of actions and interactions subsumed and lost in nursing language, yet
clearly exemplified throughout the patient narratives.

Anna’s story

For example, the fieldnotes reveal the complexity and innate value embedded in basic
nursing care, that is found in Anna’s story.

The nurse arrives. She turns the heater on, lays the clothes out to warm and assists
Anna from the bed to the toilet.

Are you weeing okay during the day?
Was this a problem overnight?
Can you manage to walk to the toilet all right?
Bowels OK? (Even the medical terms that make subjects legitimate
conversation are mutual between the patient and nurse).

As Anna is assisted to undress, subtle discussion ensues about skin lesions, as the
nurse subconsciously assesses these, comparing them (by memory) with her last
visit. The nurse asks questions and puts forward suggestions, specific to each
patient. Perhaps a medical opinion may have been suggested, or did the patient need
a podiatry appointment? Would she prefer the nurse to do her best and trim the
nails? Assessment goes on continuously.

The notation states “shower”. The taps are turned on, the water temperature altered
to be comfortable and safe on Anna’s tissue-thin, aging skin. The soap Anna likes is
located and she is assisted to wash and dry. The level of assistance is not decided
analytically, rather it is at another level of knowing in a subconscious, tacit or
intuitive way; and the continual discussion and observation reveal that the assistance
is to the level at which the nurse assesses the patient is unable to do a task without
assistance. Ointment may need to be applied, a wound assessed, and bandages
applied to swollen limbs. The patient may be assisted to dress as assessment of limb
movement, balance and general wellbeing continue. Finally, the medication due is handed to Anna with a glass of water.

As she drinks this, the nurse refills the dosett for the coming week and casually inquires if Anna is managing her medication on her own. The patient’s response, however, leaves the question unanswered...

(Patient) Would you like a cuppa?
(Nurse) No thanks, I’d better get moving, it’s one of those days!

Anna wanted to talk; I wonder about what? Whilst listening to a patient for cues about how they manage is deemed acceptable (whilst they concurrently perform tasks), the nurses have their own set of limitations; variable, depending who the patient is. Having a ‘cuppa’ was not accepted as legitimate by the nursing service or the employing institution.

Fieldnotes describe the continuation of nursing work, as Anna’s supply of medications is checked, at the same time as the nurse-patient conversation takes place. There are no potassium tablets left after the dosett is filled and no more scripts. The nurse mumbles that she will organise a script, have this delivered to the pharmacy and collect it on her way here tomorrow. If the patient was more able, the nurse might encourage her to do this herself; the nurse assesses the situation, decides on a course of action and does it.

Reflective fieldnotes reveal the simplicity enmeshed with the complexity, inherent in basic nursing care in Anna’s story:

Basically the nurse provided hygiene but it went beyond that. There were discussions about physiotherapy; how they hold that hand, how the best way to do this might be, how the patient felt comfortable doing something, how they might improve on it. There were no issues of force or dominance, just suggestions and conversation.

Margaret’s story

Margaret likes an early visit too, explaining “...the nurses simply pop in and say hello”. The inscription in the nursing notes states “daily check” and the nurse expanded on the interpretation, explaining that she would stop each morning when she passed Margaret’s house. Usually it was just a quick visit to ascertain if all was well, through a brief assessment of her general health and wellbeing. For example, they visit to check Margret is up and dressed, able to stand, that she has eaten, and any nursing is provided as necessary, in a discrete manner. Margaret’s condition
fluctuates, as does the dementia that is initially not obvious to the observer. Margaret thinks this is a social visit “...so nice of them to still drop by”, but there is a preventive nursing element for a lady who forgets who she is, to eat, or take medication. A familiar nurse visits informally, but ascertains what is needed on that day, as she says good morning and checks the tablets in the dosett.

It is not paternalistic. Most nurses do not make assumptions about Margaret’s level of functioning, as it fluctuates day by day. The discrete non-confrontational manner of the nurses means that she accepts their presence and assistance. This story is also a distinct example of meeting nursing goals described in the mission statement, of maintaining and enhancing a person’s quality of life by enabling them to remain in their own home.

**Jim’s story**

Jim has very different nursing needs. Some of his nursing needs are obvious to the nurse observer but, beyond these, he chooses not to tell the nurses (or his family or doctors) about recurring health issues, because of his desire to remain at home, independently. Jim was wary about telling his story but willing to participate in this inquiry to make public the value of nursing.

Jim explained that he appreciated the nurses coming as he knows they will arrive regularly. A few weeks prior to our meeting he had collapsed at home, necessitating emergency admission to hospital. Recently he had been discharged and referred to the district nursing service for “assistance with hygiene”. Jim was aware of his unstable balance although only conscious of his short term memory loss from events that his son informed him about. Jim’s goal was independence. He explained that he hid ongoing health concerns so he could remain at home - he was in the process of rebuilding and adjusting his lifestyle to regain independence. He planned his day around the nurses coming, because he was simply so grateful for their service.

Jim was a real gentleman. He was particular about being ready and waiting (for the nurse) in his dressing gown, so undressing would not waste nursing time. The nurse provided basic nursing care but, as was usual, this encompassed a great deal more than showering Jim. The nurse asked questions to get a picture of how much he was able to remember, how he was managing (such as what he was eating) and observed his stability as he walked down the narrow passage to the shower, how he moved his left side as he washed himself and his general wellbeing. His blood pressure was monitored and the dosett checked.
Jim felt the value of having the district nurses come was immeasurable. The value he articulated was not in the tasks they performed (although he was very appreciative of these) or assessment (as he was unaware of this), but their value was encapsulated in security. If he was unwell, he knew the nurse would come and he could talk to her. He deeply appreciated their caring attention and knowledge base, being quite confident in his belief that, if he collapsed again the nurses would arrive as usual and would know what to do, and would act quickly.

I observed and listened, coming to learn that the nursing he received was in response to his needs. The written nursing notes did not reflect the insight of the nurses and their silent pro-active assessment. The depth of nursing that illustrated that the nurses appreciated Jim’s physical and emotional needs was never given voice, but then, that was how he wanted it. The nurses relied on intuitive and tacit knowing to provide nursing silently and artfully. Jim did not tell the nurses about the ‘strange feelings’ but the nurses were constantly listening, observing and inquiring. The nurses could articulate the variety of needs and rationales that Jim held, and these were acknowledged with respect, though tainted with concern.

At the time I was challenged by my ethical obligation (as a nurse) to break my confidentiality and alert the nurses to the problems Jim was experiencing; I knew I could not, morally, risk his health. However, as this nursing narrative notes, I was observing alongside the nurses. During informal conversations with the nurses and from reading the nursing notes, it was clear the nurses were aware of Jim’s strange feelings. Jim was back in hospital a week after our last talk. I felt a strange sense of loss, but as I reflect on the manner in which the nurses provided basic nursing care, I observe a complexity in the nursing assessment and the way nursing was provided, which enabled Jim’s values and personal integrity to remain intact. Basic nursing care provided Jim with a quality of life way beyond mere hygiene, and a quality that had uniquely been his choice.

**Challenging Environments**

Not only is nursing unique to each individual patient, so are the environments of the home and a patient’s relationship with their home environment. Regardless, the home is the place where district nursing occurs.

The nature of each patient’s home, such as the size of rooms, cleanliness of the setting, facilities, temperature, and the totality of the environment, impact on the way nursing is provided. These material attributes affect the use of equipment and aids,
and the ability to move about safely (such as transferring a person with restricted bodily functioning). They also affect procedures that need a sterile environment (such as, injections, dressings or resiting a syringe driver). Homes are not sterile environments with wide passages and accessible bathrooms and so ingenuity, creativity and adaptability are essential assets of the district nurse in patients’ homes.

This was the subsequent challenge as the day continued and the nurse worked her way through the patient list. In the next home conditions were stifling, but the couple who lived with and cared for the patient seemed oblivious to the surrounds. They swept the accumulated bits from the chair, offering me a seat.

Flies were thick in the bedroom and a stench filtered through layers of linen as the patient (Sarah) muttered to the nurse. The nurse spoke with Sarah, explaining each move, to enable the elderly lady, whose body was stiff, overweight and obviously racked with pain, to manoeuvre herself out of bed onto the commode chair. The nurse assisted as much as she was physically able, as moving was a strenuous and difficult task for Sarah, but assistance was limited by a lack of space. The patient was wheeled into the bathroom and transferred onto a home-made swing chair which rotated as the nurse pushed it around over the bath. After the nurse had scrubbed the patient, leaning over the high-sided bath, this same procedure was used to get the patient out. Then the nurse dried the patient, pulling back the chair and lifting each leg gently. Ointment was applied, a test completed, a clean nightie put on and then the patient was wheeled back to the bedroom. The nurse stripped and remade the bed with hospital linen - the old sheets were tossed into the ‘foul linen bag’ for cleaning at the hospital linen service. Finally, with immense physical effort, the nurses transferred Sarah back to bed. Her back was dried again, she was made comfortable and soon drifted off to sleep.

The meeting of these patients’ needs meant an exhausting physical workload in a short time span for the nurse. This environment presented a physical hazard as the floor was littered in chaos. It was more than hard physical work as the nurse pushed the commode, transferred the patient three times during the visit, and stretched over the high edge on the bath. They changed foul linen and remade the high bed against the wall; leaning, stretching, talking, watching, and listening to meet Sarah’s needs. There was no lifting equipment, and no room anyway, and so that’s how it is.

Sarah indicated a preference to be left alone. She did not choose to have the nurses come, to coax her out of a warm bed and spend the following thirty minutes being interfered with. Fresh cold starched linen had replaced the comfort she had been
coerced to leave. Apparently Sarah had been adamant about staying at home, despite her failing physical condition, so now family members cared for their mother with regular physical and emotional support from the district nurses. The most significant impact of the nurses coming, according to the family carers was that it became possible for them to manage, physically, and keep their mother at home. As they stated,

I couldn’t manage ... I would have to put her in a home, there’s no doubt about it. [The nurses enhanced the coping ability of the family as] ... you get the reassurance ... you wonder should I be doing this or that ... when they come you can put all your worries on to them.

The nurses do their utmost to share out the workload. Nurses look after each other when it comes to lifting, and primary nursing is used creatively, by alternating ‘heavy’ patients between the nurses. For example, despite living in area A, Sarah may have been nursed regularly by the nurse from area C, or different nurses as they rotate the workload. In all probability, the primary nurse or another specific nurse who gets on well with the patient takes responsibility for making decisions about any changes to the nursing process, to ensure continuity.

**Nursing in the private domain of homes**

Homes are a private domain in Western society. Patients differ in how they feel about their homes and this, in turn, impacts on nursing in the home and nursing access. This is most obviously reflected by returning to the notion of access. ‘Outsiders’ frequently comment on the manner in which nurses invade privacy by assuming entry; but it was rarely assumed - quite the contrary. Patients negotiate access with the nurses so they feel safe (the mode of access is not public knowledge), whilst avoiding the need for them to hurry to answer the door. Many patients moved slowly and, if they moved without careful deliberation, they risked injuring themselves. As they explained, they did not wish “to hold the nurse up”. Negotiated access, therefore, suited both the nurse (as no time was lost) and the patient (who does not have to hurry or harbour guilt about wasting nursing time).

Nurses are exposed, in a singular environment, to the patient and others in the home who may present a personal risk for the nurse entering alone. Unfortunately, nursing in the home also exposes patients to the vulnerability of allowing others into their most inner and private worlds, and sometimes they are at risk. It may be a nurse who knowingly abuses the trust endowed to nurses, or a breach of confidentiality that exposes a patient who lives alone - frail, with known routines. A risk that is very real and very uncomfortable for me, as a nurse, to acknowledge.
Likewise, patients are at risk when they are vicariously dependent on nursing for a lifestyle that means so much. In being so willing to please, patients may expose themselves to harm through such incidents as hurrying to answer the door, or not revealing that they are feeling unwell as “…they [the nurses] already do so much”. This may be the patient’s choice, but is a choice grounded in patients’ needs and a human desire to have a positive relationship with the nurses as health professionals.

**Shaping Practice**

By mid-morning so much has been done with unique complexity as the nurses work intensely, combining the physical necessities with in depth assessment and emotional support, woven into the simplicity of each patient’s life. The nurses performed much more than physical care and it is all included in the phrase basic nursing care. They consider the patient’s life style and rarely do they actually limit the nursing assessment according to psychological or functional self-care deficits. There is no consideration of additional cost or extra units of care, it is not a conscious choice or a nursing diagnosis related to a self-care deficit. They provide nursing ‘to’ and ‘with’ patients.

Patient narratives stress that the nurse is the only health professional, and often the only person, concerned with their most basic level of functioning, who regularly and reliably visits the person in their home; who coordinates their needs, who assess and sees change, who is able to do something and who actually does something.

Each nurse planned to see about four patients before tea break, depending on the workload. Everyone arrives back at base around 10.30 am for a morning tea break. By returning to base at a predicted time, the nurses explained, they could assist anyone who had not returned and, if necessary, reassess workloads. Tea break is time for interaction, information exchange about patients, families, socialising, and nursing stories. It revealed personalities, tiredness, sadness, frustration, success and humour interwoven with black humour.

It was relatively brief, everyone had a cuppa and a chat and headed off, back to showers and dressings, filling dosetts, taking blood sugar levels, and checking that people (patients) are managing. Blood pressures, medications and assessments need to be evaluated and followed through. The nurse returns to the patient list and later, when the timing fits, they drift home for lunch. Again they return to complete their patient lists, intermingled with organisational work.
Checking on Maggie

We visited Maggie simply to “check on her”. Maggie was an elderly, emaciated, fragile, lady whose chart depicted the unstable nature of her diabetes. She was welcoming, stating she needed to talk with the nurse, so she was glad it was Cath; she felt comfortable to talk about private things.

Maggie told the nurse she was going to the toilet frequently at night, and this was painful. She had diabetes and had recently been hospitalised because of unstable blood sugar levels and a urinary infection. Now, when she told the nurse she was going to the toilet frequently, the nurse asked Maggie if she had told the doctor as she had just arrived home from her regular medical visit. “No”... She did not want to bother the doctor. The patient waited till the nurse came and then told her.

Cath had dropped in to check on Maggie. Maggie felt comfortable telling Cath, who assessed the situation. Blood sugar levels and a urine sample were collected, the doctor contacted (as urinary tract infections are a medical diagnosis) and a pathology slip requested (as this must legally be ordered by a doctor), so the urine could be tested and the type of bacteria, if present, identified.

Cath initiated the tests - accessed the legal signatures then mediated - alerting the doctor to Maggie’s continuing medical problems - and commenced treatment.

This interaction conveys a great deal about the cultural role, and the communities acceptance of nurses who work in district nursing. The communication skills of the nurse are exemplified by this elderly lady and the type of things she talked of in comfort with a nurse, but would not tell the doctor; and it speaks about the value of assessment and action, from a deep knowledge base, by those who know the person well and visit regularly.

Cath increases the frequency of checks by the nurses, completes the documentation and informs the following shift. She notes the time frames to follow up the urine results. A prescription is collected from the pharmacy (as the doctor ordered antibiotics and sent the script to the chemist) and the tablets are taken to Maggie. Cath talks with Maggie about the problem of going to the toilet frequently at night, explaining that she has spoken with the doctor and now Maggie needs to take the new antibiotic tablets tonight and in the morning, and to drink a lot of water. Cath departs when she feels comfortable that Maggie understands and explains that another nurse will drop in this evening and that she (Cath) will be back in the morning.
Now it’s about an hour later. This simple check (one unit of care) included basic nursing care, technical procedures, assessment; liaison with the doctor, pharmacy and pathology; and arrangements for follow up nursing and monitoring. Visiting Maggie provided nursing and medical treatment and was pro-active in minimising complications. Maggie had a health professional she could comfortably talk with, who knew what to do, and did it. All of these actions and interactions combine to enable her to continue living at home, as is her desire. This was not in the allocated workload, so the nurse is ‘on the run’; nonetheless, it is what (most) nurses do.

Workloads and caseloads never allude to the potential nursing required. Nursing is about the unexpected, and it is expected that whatever happens will be managed by the nurses within their given shift, inclusive of normal time frames and workloads. Nurses tend to accept almost any expectation and patient allocation without question.

Maggie’s story exemplifies the complexity of the nurse-patient interaction and of the nursing skills required to appreciate and act in accord with the seriousness of the conversation. Entwined with this is the dual role of the nurse who, knowing Maggie won’t tell the doctor, becomes the mediator. This example reveals a great deal about what a nurse does, how it is done, and how all this occurs to construct Maggie’s reality. Perhaps, too, this incident highlights the way nursing is a part of our society’s culture, wherein nurses practice with initiative and autonomy and patients appreciate and expect this.

Likewise, although district nurses practise independently, the ambiguity lies in the fact that how this is done, is already formed by the medical profession, as are the limitations of professional nursing practice (Gardner and McCoppin, 1986; Trueman, 1990). The nature and construction of practice is shaped by doctors who define health problems and decisions about how these will be managed.

This is exemplified in yet another patient story. In this instance, the nurse showered the patient and commented on her moist cough. The patient acknowledged this and the need to seek medical assistance. It was the nurse who assessed the patient and organised an appointment, insisting that the doctor needed to see this patient soon (despite the secretary’s response that the doctor had been on holidays and was now booked out for the next week). Later, when the nurses returned to the base for handover, they conferred, and agreed that whoever subsequently visited the patient would check that the doctor had been. The nurses worked together to follow this
through. The patient had required medication and the nurses made certain the patient had been able to obtain the tablets, that they understood when to take them, and that they were accessible, as the patient had a physical impairment.

Patient narratives exemplify how nursing assessments and actions are independently carried out. Nurses are then obliged to seek signatures from the medical profession, in accord with government regulations, laws, and expectations by society, to legitimise the actions they have already taken. In these situations, however, the nurses accept a degree of risk in acting to meet patients’ needs when doctors are unavailable, even though they act from a deep knowledge base.

**Organisational Time**

In the later stage of each shift, the nurses continue to work towards completing their patient lists: some patients preferred to be seen later in the day, others had procedures to be done four times daily (QID), and new admissions or revisits were also undertaken. Additionally, the nurse may have been running late if at any time through the shift she needed to unexpectedly admit a new patient, or had found some one to be unwell (as in Maggie’s instance) and thus, inevitably, the time taken was greater than the predicted workload.

New admissions had to be assessed and admitted. The primary nurse visits the patient in their home, discusses the patient’s needs, and suggests how these can be met. It all appears so casual. The primary nurse returns to the base and liaises with the other nurses. Together, they make an assessment of the patient’s nursing needs, based on information from the primary nurse’s visit. An estimation of needs is then converted to units of time that are viewed in conjunction with the primary nurse’s total workload and daily work patterns. The nurse who admitted the patient then returns to the patient’s home to discuss the nursing that could be provided and to negotiate an approximate time, that suited both parties.

The nurses on the morning shift continue to work towards completing their workload; finalising visits was intermingled with organisational time, hence the time of the shift was a compromise between paper work and patient needs. Paperwork represented patient notes and records that related to nursing actions, but also a multitude of information required to be documented for other purposes such as statistics (about who was visited and the number of visits), for administrative, accounting and legal reasons. Finally the am nurses confer, to ‘divvy up’ and document the management of the work loadings for the next day which is recorded in the daily work book.
Although documentation is valued as a legality and a means of demonstrating nursing provided, it rarely gives an accurate picture, as exemplified through the patient stories. Similarly, nor does the concept of a given and measured workload reflect the reality of the work performed by the nurses throughout a shift, as nursing people is not predictable. The nurses provide for patients during the initial time available, then compromise, as they tend to work unofficial overtime to complete paperwork that is generally regarded as secondary to patient needs.

Nor was the environment of the nursing base where they gathered during organisational time conducive to concentration; quite the contrary. As mentioned earlier, it was one large room, one large oval table and a ‘tatty’ vinyl chair each. There was one telephone in that room, to which all daytime district nursing calls were directed and where all six rostered nurses undertook their liaison calls. Fieldnotes reflect an ordered chaos within this environment.

There are telephone calls: one patient thought they did not have enough tablets, a relative wanted the time of tomorrow’s visit changed to suit an appointment. There are numerous phone calls made to chemists, doctors, patients, carers and families. The front door rings. The nurses answer queries, interspersed with attempts to think and write their own nursing notes. It is tidy up time, noting what’s been done, talking, and reflecting. What’s outstanding? Follow up what’s been happening, what needs to happen, organise the next day, measure and apportion tomorrow’s work load.

To an outsider, nurse-nurse interaction, as described above, has connotations of socialising and is not regarded as a legitimate use of nursing time. For example, patients and relatives invariably tell nurses about occasions when they went to see a nurse at the nursing centre. They assumed they were busy, but when they entered, the nurses were sitting around talking. But what are they talking about? No one asks, but if they did would it alter their preconceived view of what nurses ought to be seen doing? The answer would inevitably be “no”. It is a cultural norm, an accepted pattern of behaviour, that our society only legitimates nursing with visual images of doing tasks. Talking (regardless of the function) is not accepted within our society or the institution, and perhaps not even in nursing culture, so it solicits a negative image of socialising, wasting time and ignoring patient needs.

In similarity, patients did not see nurses talking with them as valuable (as they were asked in the interview) yet they frequently expressed an appreciation of the nurses companionship and interest in their families and their lives. Patients who found personal interactions valuable also felt these enhanced the nurse’s appreciation of their life and the meaning of their illness to their life whilst, in turn, these patients appreciated the nature of nursing and time constraints.
Nurse-nurse interaction is invaluable in a practice such as nursing, where communication enhances the continuity of nursing and an appreciation of patients as people. Due to the rostering of each nurse over twenty-four hour coverage by the nursing service, each nurse invariably attends almost every patient (in the service) over a period of time. It is invaluable to know how Joe is feeling when you will be seeing him tomorrow, after being in another area for a few weeks; and to know that Sue is moving slower and to allow more time for that visit. Sometimes it is an insight that can’t be conveyed in a written document, such as intuitive knowing, which is only captured in nursing talk. Despite the unquestionable value of nursing talk, it is an unacceptable image. As a consequence, it remains an illegitimate part of nursing and a silenced part of practice. Culturally, communication is an illegitimate use of nursing time.

Nursing those who are Dying

Finally, another visit may have been necessary late in the shift, as in the case of Janine. Janine was in the terminal stage of illness; she was dying and had chosen to be at home with her partner (Allen) who provided constant care. The situation was difficult for the nurses who were dealing with Janine’s physical needs and emotional circumstances and this affected the nurses themselves. Yet, there is still work to be done back at the base - the nursing notes and statistical documentation. The stress lingers in the staff room, but there is no time, nor any acceptance that nurses grieve for patients.

The telephone rings. The nurses answer queries as they try to do their paper work, but the feeling is that everyone is trying to cope. The air is one of sadness. The nurses must convey an outward appearance of ‘business as usual’ ... it’s assumed, a given fact, that the nurse’s day continues on. This is part of the job, belying the poignancy of the sadness and the grief which nurses share with the family.

It had been a long, tiring day when late in the afternoon the nurses returned to Janine’s. The nurse from the morning shift visited again, accompanied by the nurse on the afternoon shift, so that Janine and Allen would know the nurse on duty and she could be familiar with the situation and the patient.

Nursing inevitably means an intimate relationship and the nurses get to know the family and patient and they, in turn, rely on the presence, support, friendship and understanding of the nurses. My own journaling reflects on my nursing experience of caring for many dying people in their homes and brings to life many of the issues for nurses.
When a dying patient becomes incontinent of faeces and urine, and the skin is a lifeless tint of blue, nurses perpetuate a silence; “... be discreet, the family aren’t used to this” (you don’t want to increase their burden). Clean the patient silently and gently, make them look comfy, talk to them to hide any fear for anyone, add the powder, spray the room and fold the clean linen under the chin. The odours and the washing are whisked out in a plastic bag and the trauma is dealt with by the nurse later, back at the centre.

It is also interesting to reflect on nursings’ historical background which captures a distinctly similar essence, as Hagger noted, “Historically, the sick chamber was a place of hushed voices, quiet movements, and few visitors” (1976, p.39).

I return my thoughts back to Janine’s home: The nurse quickly walks back into the house as time is running out this shift, yet her manner is quietly respectful of Allen’s mourning. The doctor is rung, the analgesic order increased and the syringe driver is recalculated. Vicki listens to Allen, to his fears and sorrow, mixed with emotional and physical tiredness. A social worker referral could have been made, but the nurse is there now. She will listen. When a patient makes a decision to remain at home with their family, when they are dying, the nurses become the crucial factor in enabling this to become a reality and for ‘a comfortable death’.

Janine died that afternoon before our shift finished. For once, as a nurse, I had a chance to grieve - I was not the nurse who had to tell the family and wash the body, but I understood. The difference was that this time I could stand back and see the affect on the nurses. I felt frustrated. No way of helping, just an observer, and who wants to be observed in grief?

Memories lurk, as you never forget being with a patient and the family in the last stage of their life, the last few hours, or as they die. Emotional ties are drawn, especially in small communities. The family never forget the nurses involved and the nurses are in an unenviable position, as patients or their family are frequently also friends. It doesn’t matter even if you don’t know them, or even don’t like them, it’s simply what you do. Years later something catches your attention and reminds you of the deep blue, blotchy skin, the struggle to breathe and the odour. It may be of that one patient, or of many.

Research reflections written the afternoon of Janine’s death, as I sat in the staff room, acknowledge the incongruence of nursing’s hierarchical structure and nursing as an interpersonal action.
So you cost in time. Sometimes the nurse sees the patient quicker, sometimes it is slower, so we have an average time that we can cost. It relates to need’s analysis, managed or packaged health care, resource allocation and efficiency. But what about time for unexpected admissions, extra calls, unexpected finds when you go into the home - such as patients losing their tablets, their towels, their clothes, and trouble obtaining the right equipment? Time for death and time for grief?

But despite these late visits and the personal feeling of a desolate death, the work must go on. I recall a nurse wishing to stay with a person who was dying. There was no option - the book work must take precedence over grief, but we all knew she’d go back later, after work. Extra visits tend to be made in personal time, and nurses know that this is how it is.

The PM Shift, a Different Focus and Different Needs

The afternoon shift, referred to as the pm shift, continues to provide nursing to patients in their homes, only the nurse’s routine alters as does patient’s routine, due to the time of day. The afternoon nurse commences at 1 pm and this shift commences with a brief verbal handover, then the nurse sees patients in the shire area (the surrounding 20 km radius) from approximately 1 pm till 4 pm. In effect, this means that if a patient was ‘a double’ (required two nurses), then assistance is available by the nurse who works as the reliever on the am shift. Additionally, whilst the pm nurse is covering the shire area, the am nurses, who are generally at the base doing documentation and organisational work during this time, could also meet any emergencies or unforeseen needs in the town area.

The area covered by the shire significantly alters the pattern of the shift as a great deal of time is spent travelling. When the nurse completes the shire run, she returns to base for a quick verbal handover of any patients who may need to be visited again that evening, such as, you will recall, was the case in Maggie’s narrative. The pm nurse then visits the patients who are listed to be seen during the afternoon, across all areas of town, covering all the geographic divisions, until the work is done. In general this coincides with the time the shift is due to finish at 9.30 pm.

Vera’s Story

Vera is a shire patient; a delightful lady who is passionate about her grandchildren and the farm where she has lived for many years (that is over 20 kilometres from
town and the nurse’s base). She was discharged from hospital, after a recent stroke, and referred to the district nurses for hygiene, showering, rehabilitation and ongoing assessment, to maximise her rehabilitation from left hemiplegia.

When we arrived, Vera did not greet us at the front door as was her usual way. We found our way to the backdoor, knocked and entered. Vera was in the kitchen and explained she had not been able to get up after sliding over (she insists she did not fall). She pressed the personal alarm that hangs around her neck and a neighbour, who lived a few miles away and who had been home, answered the alarm. The neighbour assisted Vera onto a kitchen chair, talked for awhile, and then returned home at Vera’s request. When we arrived she was still sitting on the kitchen chair. She explained she had decided to stay still - she did not want to trouble anyone and she knew the nurse would be there within half an hour.

Basic nursing care, hygiene support and ongoing assessment resumed after an initial check for any pain, skin lesions, or apparent injury from the fall. Vera asked the nurses not to tell her family and this was accepted, but they explained that they needed to notify the doctor - it was routine and they believed it was necessary.

Vera was over eighty and lived in a granny flat on the farm. It was an isolated rural farm, yet Vera was forthright in informing me that this setting was her chosen lifestyle. The amount of nursing allocated was less than a town resident with a similar deficit who lived alone. Vera knew this. She had family and friends who lived in the town and whom the nurses attended, and they had talked on the phone about the differences, but Vera regarded an independent life in her own home as irreplaceable. She is simply very grateful for any nursing that is offered. Vera explained,

> It’s a relief. I don’t dress these mornings ... Sometimes I have a sleep in on that morning. I had a sleep in this morning. I get up any time after six or seven - whatever time I wake up, and go to the toilet - then I have breakfast in bed. I went back to bed this morning and then I got up a little after eleven.

I had met Vera about six weeks prior to this interview. We appreciated each other’s values and, in commonality, we both found great pleasure in living in rural isolation. After the interview we sat and talked and she related more about her experiences as a patient and the meaning certain interactions held for her. Because she wanted to remain at home, she feared any injury or becoming reliant on her family. One rather poignant story concerned the struggle of getting on with life when she felt tired and
very fragile. Vera recounted how the rehabilitation physiotherapist had suggested she try to undertake more hygiene and dressing activities when the nurses were at her home. She stated that she responded to the physiotherapist with the following explanation:

(Vera) I said when the nurse comes, as a rule, she hasn’t got time to be standing by because she’s got to go on to another job. He said I suppose this is understandable. The nurse today, she’s going somewhere else and it’s not up to me to hold her up. I find the nurses very satisfactory.

Besides, [Vera continued later] - I become so tired as every small task takes so much effort. When the nurse comes it’s like a holiday. A sleep in and assistance with my wash.

The nurses only came twice a week but this break gave her the energy and the will to persevere. As Vera continued, I noted her concern in even talking about relaxing when the nurses come: - she remarked that she didn’t want to be seen as lazy, undeserving, or not trying (as this is a breach of the cultural norm or expected pattern of behaviour of helping oneself) but, it was her means of coping. These comments, however, add further insight into the relationship between being a patient and nursing. Her needs were culturally legitimated as she had a profound self-care deficit, but she was over eighty years old and found the concept of rehabilitation too difficult, just too much. Apart from meeting her physical needs, nursing was a respite from the mundane struggle that her life had become. She found great pleasure in the companionship and support from the nurses and this small degree of respite enabled her to get by in her own home. This was her greatest value in life.

The Dilemma of Distance

As illustrated by Vera’s narrative (which is representative of many patients’ experiences), the shire run presented dilemmas about equity of access for patients. It placed the nurses in the position of making harsh decisions that were about money, but in effect, impacted on the amount of nursing they could allocate to shire patients. Travelling time was dead money. Travelling costs, inclusive of the nurse’s time, petrol, and mileage, skewed the amount of nursing that could be provided for any given dollar. The nurses creatively stretched resources by grouping patients in close proximity, then visiting a different area for the shire run each afternoon. This decreased the nurse’s travelling time, whilst the mileage was decreased and shared. Sometimes isolation, distances and the nature of a patient’s needs made this difficult
and yet, again, decisions about the frequency of nursing and allocation of scarce resources, arose. The following note from fieldwork, reflects the sheer amount of nursing time that is inevitably part of a ‘rural run’.

This afternoon it took about half an hour to arrive at the home of the first patient and half an hour to provide nursing. It was then ten minutes to the next patient’s home, where two nurses took an hour working together to care for this patient; then a twenty minute drive returning to town.

This scenario from the research equates to twenty three units of time, yet only twelve units of direct nursing. It was left to the nurses at the ‘coal face’ to decide how time was allocated. This presented dilemmas for the nurses. On one hand the bureaucrats argued that the nurses had the autonomy to provide nursing which they assessed as necessary, within the constraints of given resources. On the other hand, the unacknowledged trade off was the clinical nurse’s sense of equality and closeness to patients, along side the harsh reality of limited funding that was already stretched to meet patient needs. In this instance it meant that eleven units, or one hour and fifty minutes, were spent travelling; time that could not then be used for nursing.

The Shape of Practice on the PM Shift

The pm nurse would complete the shire run, then visit patients across the five geographical areas that made up the rural city. Some patients preferred an evening shower, whilst there was an ongoing list of wound dressings, eye drops and a variety of procedures. There may be patients who needed to be checked, if the morning nurse had expressed concerns; plus evening blood sugar levels, and medication or insulin accordingly, as these patients frequently have failing eyesight, are frail, or simply unable to learn about this necessary procedure at their stage in life. Procedures such as blood sugar monitoring and insulin to scale are important to health maintenance and as a preventative measure. If this is not checked and treated, patients run the risk of a coma, or of compounding health complications. In this way, a seemingly simple procedure draws on a complex knowledge base to provide pro-active nursing.

When the timing fits, the nurse drifts home for her tea break, then returns to more procedures: Barb’s bd (twice daily) dressing seemed to have remained a necessity for years, due to a chronic condition; Bill required a visit to be sure he had eaten his ‘meals on wheels’ and a BSL (blood sugar level) was taken and pm insulin injected accordingly. His vision was almost nonexistent and his mind wandered but this support (he told me one day when his mind was clearer than usual) made it possible for him to remain in the privacy of his own small flat. It was small, dingy and smelt...
stale, by my standards, yet as Bill said, the nurse’s visits enabled him to maintain his life. He wanted nothing more than to live at home - alone. These were his values, his needs and his chosen lifestyle.

Finally, in similarity to ward routine where patients are transferred to bed at a predetermined time, patients who needed a double transfer to bed (due to their weight or immobility) were assisted by the nurse and an orderly from the hospital at a negotiated time. It was imperative that the time suit the nurse and the hospital orderly, to fit with existing workloads, and, because of the time frame, it also followed that the patient needed to be resident in the town area.

Equity of care can only be a reality when there is access, and I soon accepted that those who lived outside the town had very different allocations of time for the direct delivery of nursing. It was essential that patients who were assisted into bed, live in the town and fit with the institutionally constructed routine or they could not have this need met.

Fortunately Mavis lives in the town area. She has an advancing, debilitating disease and is tired by seven, needing a change of position before her buttocks become red and the skin broken from the static pressure of sitting all day. One family member, a young teenager, lives with her. The nurses performed the physical tasks of lifting and transferring; intimate invasive tasks such as ongoing assessment of her health, skin tone, pressure areas, treatment to prevent any skin breakdown and ‘toileting’; plus emotive support such as talking, suggesting and listening. Mavis understands her predicament and freely talks about issues, explaining that knowing the nurses will arrive regularly provides emotional, physical and personal support and security. She expresses gratitude that the nurses have so much knowledge and that they use their initiative, as she describes the nurses quick, down to earth responses to falls and accidents she has experienced in the past. Beyond all these issues, having the nurses come, means that Mavis and her family can remain living at home living together.

Finally, the pm nurse returned to base to complete paperwork and documentation. The hospital would answer all calls from 9.00 pm until 7.00 am when the nurses returned, and the routines began again.
Chapter Six: The Nursing Narrative:  Page 127

**The Nature of Practice and Imagery**

This public image of district nursing as mundane and simplistic, typified by the washing of an elderly person in their home, of needing limited skills and knowledge, was shattered only when people were exposed to the reality of choosing or needing to be nursed in their home, or when someone close to them sought home nursing. Likewise, many nurses hold this simplistic idea about district nursing, but this view was challenged when they were rostered in the district nursing service and the variety and complexity of basic nursing care in a patient’s home environment became a reality which they, as a nurse, had to adapt to.

One nurse was reflective, explaining that

... the most different aspect is the way people are approached in their homes, in comparison to how they are approached in the ward. In the wards you would say just do this and do this and do this - this is what you must do. But that is simply not how it occurs. In the home we have to re-evaluate our whole way of thinking. [People and nurses are] ... socialised into the way we are within the hospital [but] when we go into people’s homes perhaps we accept a different sociology despite the fact that what goes on in the hospital should be the patients’ wishes as well.

**Summarising the Nursing Narration**

As this narrative has focused on nursing it has met the first cited aim of the inquiry, to record information which is at risk of becoming lost, by exposing and making public what occurs in everyday routine nursing practice. It also begins to reveal how culture shapes people’s lives and the cultural complexity embedded in such a seemingly simple act - nursing.

Some of the nursing actions are obvious, yet remain silenced, such as the value of nurse-patient communication and many intimate, private interactions. Actions and interactions that are an essential part of nursing, but breach the cultural norms of our society and are not articulated. They therefore occur in creative, integrated ways, subsumed within normative actions that are legitimised by society. In generalising, even as nurses, we do not value the art of assessing, or the complexity and variety of tasks completed when a patient is showered. Clarity and value were highlighted through the stories of Anna, Margret, Jim, Maggie, Vera and Mavis, as I watched and listened. Basic nursing care was so complex, but it does not have the valuable profile of mastering technology, and it is very personal and therefore it cannot be made public. Physical tasks, verbal questions and simple patient-nurse cues came to life when, as a nurse researcher, I could observe and reflect upon nursing.
As a researcher familiar with the culture, observation, discussions, interviews, fieldnotes and reflectivity wove depth and value to simple tasks that are, in fact, complex; combining a deep knowledge base with the sensitive use of interpersonal skills, intuition, encompassed by tacit and taken-for-granted knowledge from experience. It is constant maintenance, assessment, prevention or intervention, from a complex knowledge base, with understanding and acceptance of people, their values and their lives, that is referred to, in the culture of nurses, as basic nursing care.
CHAPTER SEVEN

PATIENTS’ VOICES

Tomorrow I am Going to Re-write The English Language

Tomorrow I am going to re-write the English Language. I will discard all those striving ambulist metaphors Of power and success And construct new images to describe my strength. My new, different strength.

Then I won’t have to feel dependent Because I can’t Stand On My Own Two Feet And I will refuse to feel a failure Because I didn’t Stay One Step Ahead. I won’t feel inadequate When I don’t Stand Up For Myself Or illogical because I cannot Just Take One Step at a Time.

I will make them understand that it is a very male way To describe the world All this Walking Tall And Making Great Strides.

Yes, tomorrow I am going to re-write the English Language Creating the world in my own image. Mine will be a more gentler, more womanly way To describe my progress. I will wheel, cover and encircle

Somehow, I will learn to say it all.

This chapter now describes experiences of being nursed from the dominant voice of the patients. Patients’ narratives explore the experiences of being a patient, revealing common issues which give meaning to and subsequently shape the experience of patients who are recipients of district nursing. Firstly, the overriding desire expressed by the patients was to stay in their own home, connected with their family and everyday life, whilst receiving nursing care. Secondly, but with slightly less control, was the desire to have a good personal relationship with the nurses; preferably a reciprocal relationship.

The previous chapter, *A Nursing Narrative*, was written around the structure of a nurse’s day, to reveal the culture of nursing, grounded in nurse-patient interactions. Many experiences were revealed, each informing us about being a patient, the experience of being nursed and nursing from the dominant voice of nurses because, as I was to realise, nursing is structured around and constructed by nurses. Now, the narrative of *Patients’ Voices* frees me from my role as a nurse, enabling me to feel with the patients, accepting, unconditionally, their experiences of being nursed. This cultural layer is informed by patients’ perspectives about their encounters and feelings, drawn from the fieldwork, the use of patients’ narratives from literature, and also from my own experience of being a patient. The inquiry seeks the emic perspective of patients, as insiders to the culture of nursing.

All quotes are drawn from the fieldwork and the many forms of fieldnotes described in Chapter 5, unless otherwise referenced.

**Introducing the Patients**

The term patient was the folk language used by this cultural group in reference to people who were recipients of nursing in the home. The participants were predominantly female and ageing, although the youngest was in their twenties. The eldest was in their nineties. Elderly patients tended to live at home, alone, as their partners had passed away. The youngest and eldest participants both lived with their families who were also their carers.

As in *The Nursing Narrative*, participants were given a code and then a pseudonym. Later, ‘kinds of patients’ were grouped together as in the following table. Themes and subsequent patient narratives that illustrate the themes, are therefore representative of a compilation of patient stories, consistent with ethnographic analysis and to maintain participants’ anonymity, in accord with ethical considerations.
The first group included many of the voices of patients we have already heard, such as Maggie, Jim and Vera. Most of these patients needed assistance as a result of the normal ageing process and chronic conditions associated with age, which is noteworthy, as they tended to accept their condition or loss of function. They chose to stay at home, were dependent on the nurses to continue to achieve this goal, and this need overrode any other factor. To this end, they were warm and inviting towards all the nurses; they tried to be ready and waiting, they knew each nurse’s interests and talked about these when the nurse came, personalising her visit. They are given further voice in Ellen’s story later in this chapter.

The second group generally needed nursing because of chronic, degenerative and terminal conditions. They struggled with this complexity in their lives (alongside grief) as their dependence was not due to normal life processes but unexpected changes to their health. Overall, to be good patients, they willingly made many compromises. They appeared passively compliant and this was an accepted position of their choice - only on rare occasions did they express frustration about the constraints on their life or about the nurse-patient interaction. This group are represented by Scotty and Sandra’s story.

The third group were similar to the second group as they suffered with degenerative and chronic and terminal conditions. Their perspective on being a patient took on a different focus however, as they tended to be younger, and experiencing various degrees of paralysis and/or profound loss of functioning. These patients were dependent on the nurses for mundane bodily care which was invasive of their private bodies. Like the other patients, they sought to work in partnership with the nurses (although they knew the rules that negated the patient’s choice to be partners in the nursing process). Whilst remaining at home was their dominant value, equally important were issues such as maintaining their sense of self and caring for their bodies to avoid further injuries. They are represented by Bron and Raewyn whose narratives are also given voice throughout this chapter.

Each group introduces a level of understanding of the experience of being a patient. For example, Bron’s story allows insight into why she needed to control (or pre-empt) particular nurses’ actions. Others enabled me to understand the fear of injury as, due to their conditions, their bodies are easily injured and sense of self shattered. In common for all groups, remaining at home was fundamentally significant and they were dependent on home nursing to maintain this. Similarly, all groups sought a reciprocal relationship with nurses. Some patients simply accepted every nurse who came and how each nurse worked. Others preferred the regular nurse whom they
knew well; who knew the patient, appreciated the patient’s needs and were willing to work in partnership. In some instances the nurse-patient interaction was observed to be quite different when ‘certain nurses’ attend, as becomes clear when these patients are finally given voice.

**The Experiences of Being a Patient**

As I examined the experiences of patients from their perspective, a number of dominant themes become clear. Each of these themes is raised through patient narratives using the concept of patients’ voices, where a voice is representative of a group of patients. All three patients may be located in a particular theme, or it may be unique to a given group of patients.

District nursing patients generally felt fortunate to receive nursing in their home, as the home enabled them to maintain personal lifestyles, and to be with families or within their social networks. This personal environment also enhanced their sense of independence, privacy and self integrity. Being able to stay in their home was therefore of fundamental significance. Of course, it is not possible to generalise. Occasionally a patient expressed a preference to be in hospital; for some it was a lonely life or a long struggle, where the patient tired from the work of caring for themselves; sometimes being at home can be frightening, as it was for a patient with emphysema who frequently suffered with severe shortness of breath.

Patients commence their day in various ways, as do other people in society, but the construction of a patient’s day is specific to the individual and their situation, shaped by the extent to which their life has changed from how it used to be, but also by the degree their life is constrained and complicated by virtue of needing to be nursed. Patients are an individual visit that make up the totality of a nurse’s day, whilst the nurses visit is a singular aspect of the patient’s day. In addition, nurses work together as a subgroup or subculture which reinforces their norms. Patients are singular.

Home nursing is distinguished by the personal environment, which is the intimacy of a patient’s home. The home is representative of, and gives others access to the intimate manner in which a person and their family function, therefore, some patients view home nursing as an intrusion, as risking their privacy and their sense of self. Homes are personal space, private territory in our culture (Altman & Chemers, 1980), yet home nursing alters the cultural norm and legitimates the entry of the nurse into the home, and private areas of homes. All but two participants chose to be in their own home, and this was the dominant factor which shaped the basis of the nurse-patient interaction at the most basic level.
The concept of being a patient

The concept of being a patient, in this inquiry, is a person in the community who needs nursing. These people have needs related to health, hygiene and activities of daily living, which they are unable to meet themselves (referred to as self-care deficits in nursing language; Alfaro, 1990) and so they are referred to the district nursing service. Each person’s needs varied. They either chose not to ‘impose’ their needs and/or illness experience on others such as their family (their friends and family were “too busy”) or, as in most cases, they had no option but to seek another to meet their bodily needs. Consequentially, they were reliant on nurses, and having no choices meant the patients felt they ought to accept and comply with nurse’s expectations. These included issues such as what needs would be met, which nurse would meet these needs and how this would occur. Patients just hoped the nurses would work with them, hear their needs, that they would be treated gently and have all (or most) of their significant needs met. Additionally, patients were expected to convey gratitude and appreciation. It is the cultural norm to be grateful to the nurses.

Patients also valued being nursed. As in The Nursing Narrative, nurses were deeply valued by patients as health professionals who spend time with them, “…who can see what needs doing and get on with it.” In this way, health issues that nurses recognise as being at risk of becoming complicated, (such as pressure areas and skin lesions) were routinely assessed and treated as part of the taken-for-grantedness of practice.

Patients explained that, for them, being able to stay at home enhanced a sense of normality in their life. Some lives continued much the same as before the onset of illness but, for others, their life was altered significantly and now physical dependence conflicted with and constrained their individuality. Patients are still people who have ambitions and goals but they must struggle to fit the shape of their days with ‘negotiated times’ for ‘support needs’ (nursing). Lifestyles are rarely the ones they chose but most still want to move forward, to go out with friends, to socialise, to stay up with the family till the television program has finished, and to go to bed when they are tired or at the same time as everyone else in the home.

In reality however, they face the frustration of overwhelming change, of dependence and of expected compliance. They face a loss of control - from the most simplistic, mundane bodily functions, to more complex aspects of their life and relationships. Society deems they must adjust; they really ought to focus on a new life within the constraints of physical limitations and nursing needs.
As *The Nursing Narrative* illustrated, the spectrum of needs is captured by the folk term basic nursing care and referred to as mundane, as normal everyday patterns of needs. These nursing needs may seem basic to the lay person but, as also became clear in the previous chapter, having these needs met equates with the very fabric of life. Basic nursing care may include being transferred out of bed into a chair, followed by the provision of hygiene, showering, hair washing, drying, dressing and getting back to bed. The provision of needs embodies a particular complexity as the nursing is about private bodies. The patient is transferred to the toilet, body orifices are cleaned, their bowels are stimulated to evacuate faeces and the ‘peri’ area is cleaned. Some actions are to do with personal bodily care and intimate invasive procedures. Others, such as hair washing, are actions commonly performed by others.

**Gratitude**

In general it was a patient’s choice to be at home, but then their options were limited to home nursing, being admitted to a nursing home, or no assistance. As a result, it was essential to have a good relationship with the nurses, as exemplified in Ellen’s narrative, which is representative of many.

When the nurses visited Ellen’s home, the overriding emotion was one of gratitude. Ellen’s gratitude was personal, and very real, as the result of her experience. Gratitude was embedded in the physical and emotional interactions; strongly bound up with a sense of safety and security, and knowing that the nursing actions and the amount of time the nurses dedicated to her enabled her to remain at home. Ellen knew the day was getting closer when she would not be able to stay at home. She was satisfied with all the nurses and with the nursing provided. She liked and got on with them all, she did not mind waiting because she knew they would come, she did not mind different nurses coming as she knew them all by now and, similarly, they knew her ways. She did not mind - anything! District nursing support enabled Ellen to feel safe, clean and comfortable whilst living at home, and to remain living in her own home was Ellen’s overriding value.

Ellen found pleasure in the nurses’ visits and delight with everything they did for her. She was ageing and, although she would have preferred not to be constrained by her ageing body, the nurses came and nursing actions enabled her to remain living in her home. She had her own social networks but, having slowly lost her function over years, she was not struggling to adapt. She led a quiet life and therefore did not mind waiting for the nurses. Ellen (and those patients she represents) valued the nurses,
needed the nurses and would accept any compromise. The value of feeling clean and comfortable and safe in one's own home was immeasurable.

**Losing individuality and normality**

In contrast, other patients placed different values on their lifestyles.

Raewyn was drowning in the process of losing individuality and normality to a life dependent on the assistance of others. The very structure of each day was dependent on the time the nurse arrived and who it was, for her day could not begin until the nurses arrived. The impact of an acquired physical impairment (permanent self-care deficit) meant she was unable to move without assistance. There was no choice and no other option in life. Raewyn was ‘dependent’ and dependence implies vulnerability - she was not in control of her own body and nor could she protect herself in any way. Grief and the will to resume life conflicted with an endless physical and emotional struggle. She told me she was getting used to it and learning to be tolerant (accepting of compromise). At the same time (she explained) she is learning to be assertive, to protect herself, and not to feel so guilty about this.

Each time I arrive, Raewyn is lying on her side on a ‘Spenco’, comfortable in the small, but cosy room where individuality adorns the walls - fortunately, as looking at the four walls is inevitably a frequent occupation. The radio hums in the background. Her mind wanders, until the sound of cars pulling up and nursing chatter signify the beginning of her day.

Three times a week it’s bowel day. One nurse arrives early, before tea-break. Raewyn is positioned on her left side in the bed and two suppositories inserted pr (per rectum). Blueys (disposable waterproof sheets) are placed around her middle torso to capture the faeces. The nurse talks with Raewyn to ensure she is as comfortable as the situation allows, then, as it takes time for suppositories to stimulate the bowel to evacuate its contents, the nurse carefully notes the time and leaves.

In being left alone Raewyn has privacy while this bodily function occurs. To an outsider it may appear to be a harsh routine, but this routine served a significant purpose. On one hand, the nurse continues on her patient rounds, so this is not ‘unproductive time’. Most importantly, Raewyn is now alone in her own private room and it is the cultural norm to use one’s bowels in private. Solitude enables a degree of normality (privacy).
Raewyn lies waiting, listening to music or the wireless. Everyone in the home (including Raewyn) can smell the faeces. They know she is ‘shitting the bed’ but she cannot feel it and there is nothing she can do to alter her situation anyway.

In the meantime, the primary nurse has continued patient visits, watching the time, conscious of Raewyn’s privacy, yet balancing this with the discomfort and risk to the integrity of the surrounding skin, if she lies in this position (in faeces) for long. Subsequently the first nurse, plus the nurse who is the reliever, return to Raewyn’s home. It’s a quiet negotiated entry, calling out greetings as they enter the home and move into Raewyn’s room, simultaneously continuing the conversation and nursing procedures. The blueys and excreta are removed without reference or comment, silently respectful of what it means to rely on others to stimulate then clean up private bodily functions. It may be a means of coping for nurses and/or the patients, rather than being faced with one’s inability to manage one’s intimate body. Perhaps the way nurses manage and perform these tasks (being silent or talking about the footy) is taken-for-granted, tacit or intuitive knowledge, gained through experience. I hoped it conveyed respect and was in response to the patient’s body language, or initiation of conversation that indicated this was how she would prefer to cope with intimate, invasive nursing actions.

It is accepted by our culture that nurses perform invasive bodily procedures, but it is not acceptable to talk about these. Culture shapes the interaction. In the same vein, one can’t ask the patient what it feels like, because even asking is invasive. The same cultural sanction applies; it’s not talked about. The ethnography therefore pursues what occurs during patient interactions by re-looking at the type of actions the nurses perform, alongside the concurrent conversations and body language of the nurse and the patient. In this way we move through the research sequence and hermeneutical knowledge acquisition to acquire an empathetic appreciation of the patient’s subjective (emic) experience.

Raewyn is organised, as are the nurses, to lift her out onto the commode chair. It takes a high degree of co-operation, trust and unspoken organisation to safely transfer a person who has quadriplegia. Raewyn is moved to the edge of the bed and one nurse puts a knee on the bed, her arms under Raewyn’s and links her hands at the front. The other nurse takes Raewyn’s legs from the knees downwards. On the count of three, they keep her body in alignment and transfer her to the commode chair next to the bed.
The two nurses continue as Raewyn is toileted, showered, her hair washed, and teeth cleaned. The clothes the family have organised will be put on. Raewyn is again double lifted back on to the bed. The second nurse will have changed and remade the bed whilst the first nurse showered Raewyn. On the bed, the nurses re-dry areas, especially the back, genitals and buttocks, whilst simultaneously checking for red areas from the pressure of immobility, or where the tubes enter her body. They may ask for verbal confirmation or they may go about the tasks and chatter to each other; it depends on who the nurses are and their relationship with the patient. (Generally) Raewyn was included in the conversation. The drainage bag is attached, her clothes are in position, and now her body is raised in a lifting harness which is attached to a trolley and she is wheeled into the main part of the house. She is lowered and settled on thick sheepskins in a layback chair, from where she can now manage the remote control to the television and a drink in a spill proof container.

“Are you right? See you tomorrow.”

Raewyn was grieving for a lost life and whilst routines did provide a sense of knowing how each day would proceed, they also stifled and constructed her rare outings and even her bedtime. She understood the need for routines but perceived these as isolating her from any sense of normality. Not that she reproached the nurses, rather, she enjoyed their company, and the outside world which they brought into the home. When asked about the value of non-physical nursing actions, she responded, expressing pleasure as, “[w]e all muck around a bit and have silly fun and that sort of thing.”

Raewyn meets the cultural expectation of trying to normalise her life, yet she is frequently referred to as a difficult patient as she seeks to have a measure of control in nursing interactions.

There is another major conflict. Raewyn and many of the patients, whom she is representative of, are unwilling to accept the given routine bedtime, necessary if they want (need) the nurses to transfer them to bed, as this decreases any attempts to normalise their lives. The nursing service routine takes place between seven and eight pm. Notably, this conflict and other similar conflicts, where services are rationed and regarded as inadequate and inappropriate, are never seen as reflecting on individual nurses, rather, patients and families explained that the nurses do what they can within given resources. In these instances, the patients, families and other carers creatively address the issues and I was to hear how neighbours, council employed personal care attendants and volunteers met the needs which the nurses stated they
were unable to meet. In one instance, when the patient’s care was rationed due to the cost of distance, the doctor ‘ordered’ an increase in the patient’s nursing care, and this was met by the nurses.

**Sometimes they listen**

Bron has a profound self-care deficit. She admires and appreciates the nurses but at times there are directions, comments and insinuations she finds difficult to accept.

The nurses arrive, see what needs doing and do it; but passive acceptance of benevolent paternalism is not always the case. Sometimes both parties negotiate, know or accept what will occur. Sometimes there is no subtlety.

The primary nurse and the reliever arrived and it was evident today was going to be different. The greeting was not cheerful, but courtesies were payed and the provision of nursing began. It was all so familiar now as the fieldwork was drawing to an end after three months. The undressing, shower, linen change, being dressed, wound dressings, skin care, assessments, ointments, blood pressure, transfers etc. Today was different due to the patient’s sharp verbal rebuttal to the nurses. The nurses were given instructions and frequently corrected or asked to re-do a procedure, with the pre-empting of familiar moves.

A nurse explained “It’s not unusual; this sort of thing happens when she doesn’t get along with the nurse.”

I saw a patient who, I assumed, was seeking to maintain some authority in protecting her own body, and I wondered, as I had for twenty years, why this was unacceptable. Why is it unacceptable - knowing it’s the only form of control in their life? As the researcher, I did not feel comfortable asking the patient how she felt, in case this risked exacerbating her powerlessness, or the tensions of the nurse-patient relationship. It is not an artificial environment, it is real and Bron has no options; nursing has to go on, day after day. I could not understand why today was so different. Bron was usually a cheerful, passive recipient and I had come to understand the gratitude embedded in almost every interaction.

Bron offered further explanation later, when the nurse had left.

**She**, [in reference to the nurse] would not listen. On a previous occasion we disagreed about the position of the leg-bag. It was the same nurse - she said it was in line and told me it was not my problem. A few hours later sitting at home by myself, the leg-bag, now filling with urine came undone. Urine soaked through my trousers, filled my shoe and went
over the carpet. [Bron continued, stating that it was her problem. It was her urine, her leg-bag, her home and her dignity. Bron talked about a number of incidents that had occurred since then, with various nurses. She tries to be compliant, but the need to avoid any further indignities means that she pre-empts or corrects these nurses] ... sometimes they listen and sometimes they don’t.

Bron expressed gratitude to the nurses without whom she would have no choice other than nursing home accommodation, whilst she continued, telling of the pleasure she receives interacting with most of the nurses. Gratitude embedded within an unequal power equation, but with a persistent theme alluding to the pleasure in knowing and interacting with nurses as people, (most of) whom she greatly respects.

**Compromised lives**

From Bron’s narrative, it becomes strikingly obvious, that many patients were experiencing the need to compromise their personal integrity. Integrity is defined by Irurita (1999, p.11)

... as having control over one’s life (situation); being able to protect oneself; maintaining dignity as a human being; being an individual; remaining whole, intact, undiminished (physically and emotionally); and being in as good condition or as sound or unimpaired a state as possible.

The insidious norms that construct a patient’s reality that infer patients must fit in with the system, accept the status quo and what others believe is best for them, alongside nurse’s denial or negation of patients’ expressed needs, compromises their personal integrity. As a consequence, many patients lead compromised lives.

The book *Able Lives, Women’s experience of paralysis*, draws on narratives of two women, Libby and Nora, whose experiences as patients add to fieldwork narratives, capturing the essence of the observations.

Some of us did recognise that nurses were often working under difficult conditions of staff shortages, but many, like Libby, still did not feel that this excused the brisk and often callous attitude of the doctors and nurses ... (Morris, 1989, p.24).

[Nora explained] ... I became very frustrated and was then told I was being difficult and uncooperative. The nurses hadn’t much time for individual attention and were always in a hurry. I hated being dressed untidily and left with my clothes twisted uncomfortably around my body, but if I mentioned it, I was being fussy (Morris, 1989, p.24).
Patients cited numerous incidents where the nurse would not listen or ignored them and, in doing so, degraded their personhood, their integrity as a person. Patients feared being treated roughly or even hurried. They also feared receiving decreased nursing allocation and consequently having no choice but to move into a nursing home.

Despite this, patients explained that they had an essential need to take the responsibility (and risk) of pre-empting and correcting nurses. Patients stated they would only speak out if this was really necessary, so it was a relief when, or if, the regular nurse arrived, understanding and knowledgeable of the patient’s situation and needs. As one patient explained,

> a new nurse, or certain nurses, meant the need to pre-empt, not just to maintain control over their own body, or to limit dehumanising actions, but for their own safety.

Pre-empting was local folk language of the nurses and patients that implied the patient would ‘jump in’ with verbal directives before or during an action, in an endeavour to control what was happening.

> ... [T]hey all do not understand. Well, probably one of the most important things is they dry me properly so that I don’t have any other problems. They get used to regulating the water properly and you fear anyone burning you. They know now, most of them, especially the ones that come more often than the others. It’s better if the same ones or the ones that come more often keep coming rather than new ones.

Patients cope in their own way, seeking to get what they need, while trying to fit back in with society. Patients want to please yet, at times, frustration would surface - as occurs in the following quote from a patient interview.

> Showering is more than a task. It gets you feeling clean, it gets you [the patient] going ... it’s a little luxury and I can feel good about myself. Is a daily shower too much to ask? Most people get out of bed and have a shower in the morning, don’t they?

Sandra’s story now gives voice to the struggle many patients experienced. Her conversation illustrates the silent compromise in patients lives as they seek to have their needs met but also to have a good relationship with the nurses. The process is so subtle that initially it was not seen; I too accepted what I saw as reasonable until, with time, I became more familiar in the setting and was able to stand back and use prior knowing but not allow this to cloud my observations.
Having arranged to meet the nurse at a patient’s home, I was late, so I knocked at the usual entrance, collected the key, entered and called out a greeting. After a few calls I was able to follow the voice to the bathroom. Sandra was chair bound but in the bathroom, undressed. She explained that she had dozed off as she waited for the nurse to arrive. Sandra stated that she chose to be ready - the nurses are busy and she did not want to hold them up. Being ready (on this occasion) meant being undressed, in her wheel chair, in the bathroom for thirty minutes. From my perspective this was not partnership but dependency, and acceptance of dependency, from a person who had no options. From her perspective it was quite clearly her choice to be ready and waiting and to feel comfortable that she did not hold the nurses up - that she did what she could, as exemplified through our conversation.

“What do you do from the time the district nurse arrives? Does she [the DN] take the initiative in what happens or is it a joint thing?”
“Oh, I’d say it is a joint thing ... I go into the bathroom and I do as much as I can for myself in there and then I wait for the nurse and she comes and we sort of do it systematically. She gets the chair, turns the water on, and then I get into the chair and pull my nightie off and then she wheels me into the shower and you know - routine.”
“So you’re very much a passive recipient?”
“Very much - and I try to be always ready in there because she’s always busy so I try to be waiting for her.”

It was all quite acceptable (and normal, expected behaviour) to the patient who needed the nurses, wanted to be liked and to enjoy the company of the nurses. She did not perceive that she had to compromise herself in any way; quite the contrary, she saw it as a reciprocal relationship. She did not see it as problematic, rather as her choice. In fact it was offensive to suggest otherwise.

It is not unusual for nurses to be in a hurry. Certainly it is acceptable and frequently admired, and the nurse is now labelled as efficient. At the same time, in flipsiding this position, nurses must accept that alerting patients to the need for speed, and reinforcing this with gratitude, solicits certain compliant behaviours. Fieldnotes repeatedly describe nurses hurrying and patients being ready and waiting;

... nurses do not expect this but positively reinforce gratitude to the patient who is waiting, to families who have equipment ready etc.

Patients confirmed this accepted position in their comments, such as:

[s]ometimes the nurse is in a hurry; well it’s quicker for her to help me with the dressing than allowing me to do so much myself.
And,
... the nurses are often in a hurry, it is something you accept.
Whose needs?

Scotty was visited by the nurses for regular assessment, hygiene and general nursing care, in accord with the nurse’s assessment. He had been a patient for years and, between hospital stays, lived in the home in which he had been born; a basic, homely building with the shower outside in the shed. Despite having been diagnosed with unstable diabetes and dementia, he was determined to remain at home. Stories were told about his past, but now he frequently did not seem to hear or understand as the nurse sought to cajole him into the shower. The patient seemed to be unaware of the nurse’s questions, expectations or why the nurse was there, and it all seemed quite out of place in a person’s home. Finally all was completed and the nurse said, “[w]ould you like a cup of tea?”

The patient’s response was positive and immediate. The nurse made him a cuppa, but declined to join him as it was time to move on. Scotty had a different priority on his needs and, with some sense of humour, used the innate power of being in his home to alter the ritualised flow of nursing practice. Whilst he later explained he was pleased to receive nursing in his home, he could not accept the expectations placed on him without “… giving the nurses a run for their money”.

Scotty’s story also alerted me to reconsider whose needs were being met. According to Bradshaw’s taxonomy of needs (1972), the shower is an actual, or normative need, the cuppa a want; but nurses are employees and nursing services are specifically funded to meet people’s normative needs resulting from health care deficits. It is worth while, however, to reconsider the idea that having a cuppa with a patient is a mere social interaction. It may have provided an opportunity for the nurse to meet the person beneath the uncompliant, demented patient, by accepting and partaking in the patient’s reality, interacting as another person rather than on another level, as a health professional. Additionally the environment would have been conducive to a realistic assessment, for example, watching how a person functions gives the nurse a unique insight into the way a patient manages with everyday life; if they can move without support, how they pour the hot water, if there is food in the cupboard and if the person can reach it.

But, why is an emotional need culturally unacceptable, and how and why do nurses so quickly categorise needs and delineate their legitimacy? Perhaps it is society which actually confers or negates legitimacy.
As one nurse exclaimed,

[how would it be if we accepted a cuppa with one patient - they would all expect it. The town would talk, and we’d never get our work done then.]

“I myself chose silence”

In the book *Just a Head: Stories in a body*, MR was subject to long periods of hospitalisation as she progressively lost bodily functions. When the doctors no longer valued her body as an interesting ‘case’ which they could cure, MR returned to her home and later, to a nursing home. In the following exemplar, MR conveys the essence of how long term illness shaped her illness experience.

Because I have been ill now for a long time I have to rely on the nurses. It has been essential to change the habits of a lifetime. People who are chronically ill have to do this and it is hard to accept. When I was first ill I thought handing over my body to be cared for was not as difficult as it is now. The transition to permeance (sic) is a time of turmoil at what is lost. I think it is basic to look after yourself ...This is all taken away from you when you lose the use of your arms and your legs (MR in Fassett & Gallagher, 1998, p.55).

MR adds “... I myself chose silence. I got treated the best if I were silent.”

In reflection, it is difficult to appreciate the degree to which patients subconsciously restructure their behaviour to enhance the nature of the nurse-patient relationship and the experience of being nursed, as a mode of personal survival. This behaviour is grounded in the patient’s need for acceptance, for they want a good relationship and they need nursing. Nursing involves other people (nurses) dealing with their personal bodies and performing intimate procedures on their bodies, so they need this to be a good relationship.

**Attributes of the Experience of Being a Patient**

Issues such as compromising patients’ physical integrity and the rationing of resources, consistently appear in the narratives as they shape the patient’s experience. For example, consider the effect on patients who felt they must to be ready and waiting, who experienced having their needs rationed, receiving less nursing because they lived out of town, having the appearance of a patient with skewed clothes and so on, and being transferred to bed at 8 pm every night. As a result, patients experience dependence, vulnerability and expectations of compliance, which are now explored from the patients’ voices.
Dependence

A patient’s degree of dependence was a reflection of being unable to perform intimate bodily procedures and, as a consequence, needing nurses. Dependence was much more than having intimate body functions met by another. It also encompassed a sense of grief that this was so, a sense of powerlessness about the manner in which this was done, and helplessness at not being able to control or influence how it was done. Dependence for these patients held particular and significant meaning, captured in the notion of vulnerability. Being dependent is more than a workload, or a need, and held greater significance for patients who had no choice but to risk their personal intimate self.

Dependence directly correlated with the importance of the nursing to the patient. For example, Raewyn’s day could not begin until the nurses arrived, therefore she was very dependent on the nurses, and being nursed was an essential part of her day. The level of dependence, therefore, also equates with vulnerability for Raewyn was really at the mercy of the nurses. Apart from pre-empting the nursing actions, she really had no control over how nursing occurred, what was done to her, or the level of privacy and confidentiality. It was therefore important that the nurses who came respected her personhood for this would shape the way nursing followed and, subsequently, Raewyn’s sense of self.

Like Raewyn, many of the patients could not care for their body with any sense of normality, without the nurse coming. Certainly, they would not be able to remain at home and so, whilst they lived at home, they were on an emotional tight-robe. In essence, this notion of dependence meant that if the relationship with the district nurses was compromised they would feel (quite justifiably) that their quality of life was at risk.

**Being a patient inevitably implies vulnerability**

Irurita (1999) found that patients experiencing a high level of dependence had low control of their life situation and, as a result, increased vulnerability.

Vulnerability meant being susceptible to physical and/or emotional hurt, harm, or injury; defenceless or weak in relation to self protection, open to assault. This was related to an inability of patients to retain control of their life situation or to protect themselves against risks/threats to their integrity (Irurita, 1999, p.11).
The vulnerability of patients is directly related to their need to feel safe and comfortable, and to be accepted, during an interaction where they have limited (or no) control.

Basically, every patient in this study was vulnerable as the overriding desire to remain in their own home meant they would probably have to compromise their needs. As the degree of lack of control in interactions, and the personally invasive nature of the interaction increased, so did the degree of vulnerability.

In addition, patients breach social norms of health simply by being dependent and needing nurses to perform intimate bodily care. This deviation from the norm is acceptable (or at least silenced) as nurses meet patient needs and informally mediate between the patient and the community (Littlewood, 1991). In this manner a patient’s deviation from health is legitimised if they are passively compliant, that is, by being ‘a good patient’. Again, the notion of compromising needs to please nurses, makes a patient vulnerable. Simply by being a patient who has needs (which structure how a patient is able to live their life) and being dependent on others to have these needs met, means that all patients are vulnerable.

“I will only say good things”

From the patient’s perspective, partnership was an acceptance of a passive role, of being ready and obliging so nursing could be provided in a minimal time. Accordingly, most patients were compliant, knowing who they will need in the future. Being a good patient helped the patient feel that nursing was a personal or reciprocal relationship and that, as a result, the nurse would treat them well. Being treated well, included notions of confidentiality (to avoid intimate details being talked about), of respect (to avoid rough or hurried interactions); enhanced the likelihood of the familiar nurse arriving, helped patients feel secure that future nursing would continue (in a regular time slot), and that needs would be met.

Most patients were good patients. The nurse explained routines and patients appreciated these. They want to fit in, they don’t want to disturb the nurse’s routine or take up too much time - whatever the nurse can manage. They are so grateful and as a consequence, obliging. Simultaneously, they confer the nurse’s status with comments about how good the nurses are, as revealed in the fieldnotes:
I would not say anything bad about them - the nurses coming regularly enables [me] to stay at home;

and

I will only say good things about these girls - they mean so much to me.

These establish a dominant and recurring theme in conversation with every patient in the study. It began the day I entered the fieldwork and continued repetitiously, in various forms, till the final closure of interviews. Patients regularly commented on the positive attributes of the district nurses; the virtues of the nurse, that the nurse is a guest in the home, that needs are negotiated, and that they work in partnership with the nurse.

There were two facets to these statements. There was the need to be positive to enhance the way in which they were nursed, yet, at a basic personal level, patients genuinely want to enjoy the company of the nurse, the person with whom they spend so much time and who performs very intimate procedures for them. As an intimate, personal interaction, nursing needs to be a reciprocal relationship where patients feel they are respected and that they matter.

Over time, discrepancies appeared in this dominating theme about the virtuous nurse. Body language, incidents and general observations alluded to subtle tensions. As previously noted, these issues began with patients being hurried and compromising their physical integrity to be ready and waiting. As also previously noted, patients and families rationalised these shortcomings so that they were rarely a reflection on individual nurses but seen as the consequence of bureaucracy which shaped nursing practice, or in terms of broader notions about the health care system which disregarded the reality of patients’ needs and did not provide adequate funding to nursing services. It was seen as a system that espoused the concept of normalisation, where patients are rehabilitated to limit the impact of their condition on their life, and are expected to return to normal life patterns as far as practical. Patients and their families felt ‘the system’ espoused normalisation and empowerment, but that there was no appreciation of what this means to patients, nor were services given appropriate resources to enhance patient’s opportunities. Normalisation must fit with pre-existing routines. Patients dreamt of having “... a shower every day - or even four times a week ...”
Factors that Shape the Nurse-Patient Relationship

This section now looks at the dominant factors that influenced or gave shape to the nursing relationship as given voice in patient narratives. The dominant factors were the desire to have a reciprocal relationship with the nurse, to remain at home, and ways of being nursed.

Reciprocity

In returning to the notion of the good patient and only saying good things about the nurses, we discover that these attitudes were not only a means to end (of learning to get what you need). Most patients genuinely, actively sought a reciprocal relationship with nurses. Reciprocity enables patients to feel they are respected, that they matter, and it normalises the relationship as the patient seeks to give something of themselves to the nurse (such as gratitude and friendship). In a socialising manner, just as people integrate friends into their lives, over time, many nurses and patients develop an integrated, reciprocal relationship. Reciprocity is about treating and accepting each other as people, which in the nursing context is difficult as any socialising, even talking and listening, is perceived as an illegitimate use of nursing time. Similarly, when patients were asked if the nurses met their emotional and physical needs related to the reason they were nursed, many patients feared this implied opening up and telling all to the nurse ‘like a counsellor’. They negated this concept as unnecessary. As a result, what the nurse did and what the patient valued, or perhaps, what they felt comfortable to articulate, was unpredictable as indicated by the following scenario from the fieldnotes:

An elderly patient was discharged following major surgery and returned home, alone. The nursing support was intensive, from post operative dressings to basic nursing care and rehabilitation. When asked what was the most important thing about having the nurses visit, the patient stated “… [the] mental satisfaction knowing that they are coming.”

Fundamentally, however, the fieldwork repeatedly revealed how conversations were woven through nursing interactions. Both parties talked about their lifestyle, priorities, and needs. Nursing talk with patients regularly centred around patient’s outings and lifestyle with suggestion, encouragement and support; (generally) moving beyond the singular focus of the patient to socialising conversation, reflecting an integration of bodies, tasks, technology, emotions, and the mundane reality of life. (Generally) interactions alluded to mutual respect and concern between the nurse and the patient. Patients had many reasons why verbal interactions (as the nurses performed tasks) were pleasurable: it added a sense of
interest to their days and lives as they looked forward to the nurse’s arrival; it enabled patients to contribute as they swapped books, saved bulbs and cuttings for them, cooked them a pie on their birthday. It made the patient feel like a person, not just a patient, and made them feel they mattered.

Again it is noted that the nurse-patient interaction is an illegitimate use of nursing time. It occurred - it was valued yet it was silenced, akin to taken-for-grantedness as talked about by Lawler (1991), thus revealing a common pattern of expected behaviour (Spradley, 1980). At this point, the notion of how culture shapes and gives meaning to behaviour, becomes evident. The notion of illegitimacy shapes the behaviour (so it occurs behind closed doors and remains silenced) but the meaning of the behaviour is the cultural norm - our culture only legitimates nursing time with tasks and measurable outcomes. Finally, I could appreciate the power of culture, as captured by the phrase that, “[t]o realise the force of culture is like realising that our minds have an unconscious” (Peacock, 1986, p.46-7).

Ways of nursing

Just as this chapter is based on narratives about ‘kinds of patients’, similarly, patients described ‘ways of nursing’. When patients felt assured of confidentiality, many provided clear comment about the way a particular nurse practised, explaining why they believed she practised in a particular way. The following is the result of ethnographic analysis of patients’ perspectives and reveals how patients saw and valued nurses in different ways. This level of understanding is drawn from various fieldnotes, observations, interviews and patient discussions to reveal ‘ways of nursing’, as illustrated in the analytic tables, Appendix 4.7 and 4.8)

‘Good nurses’: Attributes commented upon by patients included: listening, it matters to her personally, they take special care and do some extra things, they are always on time when they can be (noting patients accept minor variations from these nurses). Patients talked about how these nurses used knowledge, made decisions and carried them through, accepting personal responsibility. Patients knew these nurses were sometimes taking a risk with their actions, but they admired this trait. They explained that the nurses could do this and should do this (because they have the knowledge) rather than confining nursing to routines and strict lines of accountability. These nurses give of themselves by accepting and meeting patient needs, and the patients described this as empowering and as a partnership. The attributes of the good nurse draws on the gentle caring aspects, on knowledge, creativity, initiative, highlighting respect for the patient as a unique and valuable person. Patients felt they really mattered to these nurses.
Those referred to as ‘The other nurse’ were described as controlling interactions, pre-empting patients’ moves and overriding patients’ initiatives. They were rough, slap-dash, offered no explanation, or limited explanation, or an explanation that negated the patient’s presence, suggestions and/or their experience. Work patterns were task orientated, efficiently carrying out nursing routines, accepting the system, doing what needed to be done, and clearly conveying their expectations of the patient. Patients explained these nurses follow routines; ‘speed was the essence’ and, as another explained, “...these nurses just work for the money”.

Finally, the third grouping included descriptions of a cross section of other nurses. Some nurses were categorically ‘good’ or ‘other’, but some, those who are in this group, moved between the categories depending on the patient. This group also includes those nurses who were perceived neutrally, almost as an absent nurse. They were not great partners but nor were they a threat to the patient’s personhood. Patients simply accepted what occurred, as they had come to expect it. Patients explained that the nurse has a certain role, and these patients believed (with regard to these nurses) that, if they wished to have district nursing then they must accept and do what is expected of them.

There were many variables but then no variable can be considered alone. Likewise, when the nurse and patient meet it is an interpersonal interaction and no interaction is neutral. In reality each nurse worked from a multitude of ideological underpinnings, frequently a combination unique to that nurse herself and the patient with whom the interaction was occurring.

‘Someone special’ was the language patients used to describe nurses who practised in a particular way, that moved beyond the generalised themes. It is not a category, but insight into the way some nurses work, with reference to two specific nurses. A higher level of understanding is gained by drawing on ‘ways of nursing’, then looking at two episodes of patient care, to find out what it was about the way certain nurses practised that was different from the norm; that is, the two common categories. These nurses were described by a number of patients as “someone special”.

...[T]he nurse waited, listening encouragingly to the stories about patients’ lives and how problems occurred. Tasks were completed without an air of speed and efficiency. Regardless of how slow a particular patient seemed, the conversation was never cut short and yet the work was completed and assessment continued throughout. There were no issues of dominance, just quiet suggestions and a comfortable rapport.
The nurse knew the patient and their routine, but did not proceed automatically. She followed the patient’s lead, respectful of how she felt at the time, asking questions about what they would like. How do you like this done? Do you like powder? Patient individuality and respecting their mood was reflected as a two-way process rather than either person taking the initiative.

The field notes capture the essence of why the way these nurses practised was different, through the concept of listening to and accepting of the patients story of their illness experience, shaping the way they practice around a patient’s needs and feelings. This was no dominance but rapport that was “… respectful of how the patient felt at the time.”

**Being in the home**

Yet again, the discussion returns to being at home as a dominant factor that shaped the nurse-patient relationship. Whilst the fundamental significance of being at home has been established, the hermeneutical spiral of knowledge acquisition and ethnographic developmental research sequence, simultaneously seek another level of understanding which leads the inquiry to ask *‘but why is the home so fundamentally significant’?* It has been found that needing nursing and not knowing when the nurse would arrive altered patients’ routines and lifestyles. It has been suggested that nursing, therefore, compromised patient’s lives, and yet it was valued to such an extent that compromise was accepted, if indeed they felt it was a compromise (as was given voice through the stories of Ellen and Sandra).

Three dominant reasons come to the fore that aid in understanding why patients chose to be at home and why they would accept certain situations to remain in the home. Each is dealt with separately to clarify the cultural norms and why they were the norms but, as nurses and patients would appreciate, in reality, these factors are interwoven and interdependent.

Firstly, this environment was their home, not a hospital or nursing home, constructed and constrained by institutional routines, institutional spaces and a loss of privacy. In comparison to these surroundings, their relationship with the nurses was personal, and therefore, whilst home nursing compromised patients lives, it was seen as less encroaching than other settings where people access nursing.

Secondly, each home reflected the uniqueness of the individual person who was a patient, and it was an environment that allowed them to be surrounded with their personal space and possessions, connected with their normal life patterns and the company of families and social networks.
Those patients who chose to be nursed at home, felt this environment enabled them to maintain certain levels of independence, privacy, and personal integrity, that would be impossible in other places such as hospital, hostels, or nursing homes. Liaschenko helps our understanding, as she explains that most of us fail to appreciate the influence of places.

"[P]laces are more than particular arrangements of space ... [they are ] symbolic constructions, reminding us of our connections to others ... [Occupying personal space Liaschenko suggests] ... helps patients maintain connections to a life across space and time that has been disrupted by disease and illness” (Liaschenko, 1994, p.19).

In addition, throughout the fieldwork, it was found that the home conveys much to the nurse about a person. Regardless of degrees of health or illness, dependence, vulnerability, lack of choice or compromise, there is the stability, the privacy and the special value of being in one’s own home. Liaschenko’s exploration of the moral geography of home care, also highlights the significance of homes as the link with patients’ everyday lives, their connections with others, self identity and motivation.

Thirdly, fieldwork also illustrated that the home is not singularly conducive to patients’ happiness, it is how they feel about their home and their degree of emotional comfort that mattered. Altman and Chemers (1980) highlight the cultural norms of personal space and privacy:

... it is believed to be important for people to have homes, and places within homes, such as bedrooms where they can retreat, where they can assume a certain image and status within a family, and within society, and over which they have relatively complete control (Altman & Chemers, 1980, p.130).

In our culture the home is a territorial base and a place of privacy and, as such, this impacts on dimensions of the nursing interaction. It follows, that the home is important to a person’s wellbeing and any loss of control has implications for self-esteem, self-identity, and the ability to function, causing an affront to the psychological wellbeing of a patient.

Building on this notion, a person’s (and therefore a patient’s) privacy is a dynamic process whereby people vary the degree to which they are accessible to others. In home nursing however, the aspect of ‘selective control of access to the self’ (Altman & Chemers, 1980, p.77-78), as the intrinsic aspect of privacy, is generally absent. The process of controlling or trying to negotiate access to the self was illustrated in Bron’s non-compliance where she pre-empted the nurse, but then the value of
privacy was diminished by the nurse who reclassified the nature of the interaction when she explained “[i]t’s not unusual this sort of thing happens when she doesn’t get along with the nurse”.

As noted in patient narratives, it is simply accepted that this is what patients must do to receive nursing; the patient waits, the nurse comes, nursing takes place and the patient resumes their day. In addition, the nursing narrative reveals the ease with which nurses enter patients’ homes in a manner, specific to home nurses.

The notion of the home as sanctioned private space was not the experience of patients who were dependent, such as Raewyn, Bron and Sandra. They asserted a preference to stay in the home environment but they had learnt to compromise their private space and to relinquish control over what occurred in the home. It was still the preferred choice to be at home, but many of the issues of privacy and control that well and able bodied people take for granted (as the cultural norm) were continuously compromised.

Other patients expressed the value of the district nurse coming as enabling them to stay at home relatively independent from families, providing a very precious quality of life. These patients did not feel their private space was compromised, rather they were grateful and reliant on the nurse coming into their home and acting intuitively with autonomy. As one patient stated,

They just see things for themselves because they’re used to dealing with patients. They notice ... and do it ... and it’s just part of it.

**Being an Insider**

Nurses (in general) are outsiders to the world of being a patient. They may have been a patient in a temporary sense, but being an insider to the experience of patienthood is embedded in dependence, vulnerability and chronicity which MR (in Fassett & Gallagher, 1998) captures in the phrase ‘the transition to permeance (sic)’. The consequence of being unable to deal with one’s personal body, or of needing invasive personal procedures carried out on your body is about knowing the fine line of being dependent. It is about sensing what the nurse expects and accepting, with gratitude, any nursing received. It is about knowing the risk if you aren’t a good patient, but at the same time, knowing what it may mean to you as a person, or to your body, if you don’t speak up.
Being an insider is about experiencing submissive compliant expectations, with no way out and no end in sight. Being an insider is also about broader cultural notions where long term needs establish a deviation from the norm of health and where one is expected to conform to the role of a long-term patient. Patients are recipients of knowledge and services, they are not partners. They are at the bottom of the hierarchy and it is the cultural norm for patients to follow what is expected of them (Palmer and Short, 1989; Sammuelson, 1991).

The language of those patients who became insiders is different too.

The nursing profession, the institutions which employ them, policy and funding bodies, all associate patient dependency with physical and technical needs and the frequency with which these need to be carried out. For nurses, patient dependency is reflected in the weighting of the workload, the time taken to provide nursing for a patient. Dependency holds quite a different meaning for patients who are reliant on the nurses for intimate bodily functions, for very personal needs. For them, dependency is about being reliant on another. It can be emotional or physical or both and holds a meaning that is highly significant and, essentially, immeasurable. Similarly, whilst nurses refer to patients and their needs from a medical framework, those patients who are insiders may use some medical terms but in their case, it was simply an evolution of language, due to the time they spent with nurses. Frequently it was also observed that the use of a medical term for a procedure enabled the patient to feel that what was being spoken about was less invasive of their person.

All these issues are tied up in nurse-patient relationships and the notion of being human. In addition these are district nursing patients. There is no problem in these people not functioning socially like everyone else in the broader community. The nurse calling in her uniform and car with the hospital insignia on the door, is the medical, social and cultural exemption, mediating their deviance with the outside world (Littlewood, 1991). Some accept the status quo with gratitude, whilst others learn how to get what they need but they also learn to mediate this with expected norms of being a patient.

The insider experience is one of understanding what it is really like to be a patient in our culture. Cultural knowledge tells us what is normal within a given group for a like or shared experience, shifting the emphasis from the behaviour to the meaning of the behaviour (Hammersley & Atkinson 1983; Spradley, 1980). The goal of ethnography is to describe and explain regularities and variations in social behaviour. The voices of patients reveal their experiences. In turn, as the inquiry looks at the
experiences of a number of patients, patterns of expected behaviour become clear and these patterns are the cultural norms. By virtue of being ‘long-term’, these patients have breached cultural norms regarding the sick role; that is, of getting expert advice, blindly following this and getting better. Being in their home and being nursed are two ways that mediate these patients back within the broader culture with acceptability.

I sat mulling over the conflict for patients: At one extreme some patients desperately want to stay at home yet on the other hand, their privacy and sense of self is so unwittingly diminished. I thought about how, as a health professional, I had never realised the invasive impact of intimate procedures and the impact of nursing on patients’ lives.

I was sitting over in the hospital section, over the street that links the home nursing and the institutionalised care. There was a small coffee shop where I sat as I pondered this dilemma and at the next table sat two women, whom I barely noticed until their voices rose. A young woman, around twenty, sat with an older lady, probably a helping professional of some description. You could tell by the, classy and yet comfortable clothes she wore with the air of a middle class professional. The younger woman appeared somewhat battered; well, untidy or out of place. It was cold and she wore thin slacks, a jumper and moccasins. Her clothes looked uncomfortable on her body, as she sat in a wheelchair drinking the coffee the lady had procured. The voices became louder.

“I’m not being unreasonable, I’m being logical! I’m going to go home.”
“But that is illogical” said the health professional.
Well what about next week - I can manage......well at least as well as I do here......it’s so awful in there.”
“That is illogical [repeated the health professional] it’s not that bad......”

I switched off, quickly moving away. I had to. There was the characteristic patient. They still have the same wants and needs as do other humans, especially the need to be treated with respect and to have decisions respected, as was probably their way before the illness. But, people control their own destiny before they become patients. The two aspects of the conversation were so familiar and I was both the nurse and the patient. On this particular day, however, I was there as a patient.

I keep reflecting, knowing that younger, profoundly dependent patients would have felt deeply for this young woman. They would understand the passion, knowing the compromises that would willingly be accepted for home to become her reality. The conversation of two very different people who attached different meanings to their words; to the whole conversation. Like nurses, the health professional must convince or coerce the girl to change her mind (without there being a scene). It is the professional and cultural expectation.

Batt (1994) remarks, “[w]e are labelled patients ... thrust into a medical system governed by undisclosed rules. Compliance gains approval - spoken in medical jargon with an infantilising ... there there dear” paternalism.
There are types of nurses, types of patients, needs, wants, personalities and limited fiscal resources. People who accept structure, people who negotiate subtly some control over the routine and yet others who choose, or need to at least feel, that they have some control over their own life. Pre-empting or disputing the process of nursing is one way, and sometimes the only way, in which a patient can install any personal authority over what happens to their own body in their private domain. Regardless of how the patient reacts, from deviance, to a partnership, to compliance, nursing is a relationship enshrined in unequal power. Patients need the nurses and they therefore need this to be a good relationship. They want to feel comfortable and accepted. They do not need to deal with a complicated or negative relationships, to get hurt, to be hurried, or feel they are an imposition. It’s their home and their personhood. Some things ought not be breached.

**Summary**

Cultural complexity acknowledges that even the simplest interaction is imbued with a multitude of cultural meanings (Spradley, 1980, p.100). Nursing does not occur in isolation and the setting is cultural, implying common patterns that shape behaviour. The patients who were participants made it explicit that mundane values such as being at home and having their needs met with respect, were the most important values for them; thus this is a cultural imperative which patients set store to. These values maintain privacy, connection with their everyday lives and therefore enable patients to maintain a sense of self identity.

In contrast, nurses are powerful health professionals and patients are at their mercy. Patient narratives illustrated how and why they compromise their needs and their sense of self in an endless quest to earn the respect of nurses. Some patients do this willingly, others struggle with notions of helplessness and powerlessness but, ultimately, it is the price of a good relationship and it is the expected cultural norm. To maintain their ultimate goals, of being nursed at home in a reciprocal relationship, each patient’s experience is shaped by their dependence and subsequently their vulnerability.
This chapter discusses the power of culture in shaping the experience of patients. The study now pursues insights gained in *The Nursing Narrative* and *Patients’ Voices* alongside the attributes of time and space as common issues which construct normative culture.

The previous narratives illustrate contrasting instances of nursing and being a patient. They show the ease with which nurses enter patients’ homes; nurses chattering whilst a patient is rolled over and suppositories inserted; nurses hurrying, rewarding patients who are ready, waiting, and easy to get on with. The narrations also reveal patients who were paralysed who feared getting burnt or their urine bag leaking because the nurse would not listen. We even recognise patients because of their unkempt appearance and skewed clothes and, likewise, we recognise health professionals with obvious middle-class imagery, conveying their expectations to a patient.

Accordingly, the study now seeks to understand the cultural construction of illness. The discussion looks at the dominant public images of health culture in the context of the community, patients, the sick-role and nurses. An understanding and awareness of the dominant images then enables the inquiry to examine how the common attributes of time and space, which consistently reappear in the previous two descriptive chapters, give shape to the norms of being a patient. Finally, this chapter explores how deviations from the cultural norms of prescribed time and space shape the patient’s experience, from movement through the stages of illness that are referred to as acute, chronic, rehabilitation and normalisation.

**The Norms of Health Culture and Public Images**

An overview of health care and health culture are now explored to make explicit society’s dominant images of patients, nurses and the sick role, to illustrate the set
patterns of these roles which we take-for-granted, as common expected patterns of behaviour to which we are accustomed.

When looking at the experience of being a patient, ‘health care’ is the folk language that encompasses the activities related to disease, diagnosis, and treatment. It includes the interactions between doctors and nurses with patients, in environments (spaces) such as hospitals and homes where health care takes place. ‘Health culture’ is the folk term that captures the dynamic interplay between the environment and participants which, over time, has formed a generalised pattern of expected behaviour. In this study, health culture focuses on nurse-patient interactions, and the expected patterns of interactions that were found to be shaped by various notions of space and time. In turn, the notions of time and space will be shown as playing an integral role in constructing the illness experience, and the norms of health culture.

In Western society, health culture is set within a social context, predominantly underpinned by the medical profession and society’s infallible belief in the biomedical model of health. These have created a dominant ideology which is given shape by health care professionals and imposed on the community. It seems clear from the descriptive narrations that, in general, health professionals shape the cultural norms but do not share their knowledge, or the norms which they construct, with the community. For example, Jourard (1971) and Lorber (1975) argue that doctors and nurses deliberately limit the communication of information to patients in order to maintain their professional detachment. In a similar vein, Coser (1962) and Campbell-Heider and Pollock (1987) suggest distancing is a measure of arbitrariness, reminding the patient they are not in a position to have any say or to make important decisions.

Hospitals, as spaces in the community where health care takes place, reinforce the dominant hierarchy of medical knowledge as they have their own culture quite distinct from the outside world. On admission to health culture, a person becomes a patient. Now, those in control, (such as administrators, doctors and nurses) are regarded as having the right to define the patient’s experience. Similarly, the medical profession are referred to as experts, with the right to determine a person’s health status, prescribe the meaning of disease, illness and how wellness will be achieved.

**Cultural images**

The images of participants in this culture are broad generalisations but, as dominant images in our minds which are reinforced by the media, literature, and society, these images are valued by the community as being true. Health culture has a dominant
image that is publicly valued as being true and, in this way, in a self perpetuating manner, this image continues to shape and give ongoing meaning to the public’s image of health culture. These representative images are now made explicit, as they enable the inquiry to come to understand what the public believe, but also because the ethnographic narratives presented so far in this study, suggest these images are exemplified in reality. For example, *The Nursing Narrative* and *Patients’ Voices* revealed the image of nurses was important in shaping community perceptions of nursing and, as a consequence, the cultural norms and expected patterns of behaviour of patients. The specific images of health culture to be examined are the community, patients, the sick role and nurses, along with the way in which each shapes public perceptions and therefore the cultural norms of behaviour.

**The community**

The dominant image of health culture in our society (especially in rural areas), gives credence to the biomedical model of health where a person with an illness or potential illness seeks expert medical advice. Subsequently the person becomes a patient unquestioningly follows the expert’s knowledge with a given expectation that they will return to health.

The meanings of health and illness at the community level, however, are given voice through political health policies. Political parties and government authorities construct health policies in conjunction with lobbying by powerful, influential pressure groups. Policies determine funding which is then tied to specific programs that are valued at a given point in time by a given community. In reality then, health professionals construct public images and political parties fund these images. For example, Illich (1977), Jourard (1971) and Taylor (1979) express concern about the insidious manner in which health care professionals create needs from the domains of disease and illness, then needs become funded units which correlate to money. The person is replaced by a disease, needs and a given amount of funding. This is a reality, illustrated by the current experience in Australia where hospital funding is attached to diagnostic related groupings. In this way only certain needs will be accepted as legitimate by health professionals and they are needs which the community, through public policy has determined will receive funding. The funding of professionally legitimated needs reinforces professional dominance.

In a cyclic fashion, this returns the discussion to the beginning where health culture and health professionals are regarded as having the right to define patients’ needs and consequently, their experience of being a patient. Simultaneously, the hermeneutic
spiral of knowledge acquisition, where knowledge is built on prior knowledge, has provided insight into why and how this dominant image is self-perpetuating, and blindly accepted by society.

In our current political climate there are two diverse images being sent to the public which shape cultural norms and the meaning of specific illnesses. The first image is one of individual accountability, whilst the other, to the contrary, promotes the message that health is not within the control of the individual person. These vastly differing ways of looking at health, illness and disease are related to specific conditions, and sometimes causes, consequently, it is inevitable that those regarded as an individual’s responsibility will produce the highest degree of social sanctions against those who deviate from the norm - health.

Conditions that are an individual’s responsibility include the notion of ageing, work injuries, genetic and acquired impairments and chronic conditions. The common factor is not that an individual could have acted to prevent the condition, rather, that these conditions, injuries and illnesses are not usually preventable or curable and therefore do not fit neatly into the medical paradigm and curative expectations. Examples of media messages that suggest individual accountability are compliance with asthma management plans, medication regimes or ‘preferred treatment’ (such as back injury is best treated with activity). In addition, in commonality with dominant public images of health culture conveyed and reinforced by media campaigns, these messages are reinforced by the medical paradigm. The messages, however, are not based on knowledge of an individual’s condition but are meant to convey the socially constructed expected patterns of behaviour.

The second image is the promotion of the message that health is not within the control of the individual person. Examples such as campaigns run by the Anti Cancer Council, suggest the individual is responsible to seek ongoing medical advice and testing. These tests are enhanced with government funding, promotion and public policy. The individual must seek pathological medical tests and results as a person cannot be well without medical confirmation. Conditions that may be detected such as skin cancer and breast cancer, have medical procedures which follow if a test shows an abnormality. Needless to say, even mass screening tests are perceived as legitimate needs, and funded accordingly, even though in many instances there is the absence of disease. This is in direct contrast to the first group who had health problems, where the promoted image is about conforming to regimes to limit the social impact of these conditions, because they are rarely curable and, as such, they do not fit the accepted image.
Patients

The dominant image of a patient is one of a person who is ill and seeks a medical (expert) opinion. The physician either negates the person’s symptoms or makes a diagnosis and treats the person, who is now referred to as a patient, with the aim of curing the disease at a cellular level (Campbell-Heider & Pollock, 1976). Diagnosis and prognosis is legitimately the domain of the medical paradigm along with tests to demonstrate the presence of disease and, therefore, the patient’s personal knowledge or beliefs are not regarded with credibility. Forms of assistance are ordered by the doctor using expert knowledge, which in many instances will then legitimise the need for nursing. The cultural norm of the patient is a person who has a positive outlook, is accepting and diligent in acting in accordance with medical advice and, who is dis-empowered and blindly accepts expert knowledge. Society’s image of a patient is reflected in the sickness role (Parsons 1951 cited in Roach Anleu, 1991) which is the accepted cultural role for patients.

The culture of patients is shaped by social expectations which are a collective value judgement imposed by society. Good patient descriptors include; obliging, cheerful, have a positive attitude, a nice personality, community status, an acceptable illness, conform to expected cure or rehabilitation schedules and are rewarding of the staff (Hall, 1994 b, fieldnotes; Lorber, 1975; Stockwell, 1972, 1984). This is confirmed in the literature, in the experiences of MR, who explains that,

In my experience, the ideal patient is one who is self caring, only requires medication and is compliant by remaining quiet (p.60). Experience and observation has taught me that demanding patients get less done for them than the compliant or passive patient (Fassett & Gallagher, 1998, p.76).

The behaviour of a patient is the result of needing nursing and so, in general, a patient’s behaviour is directed to elicit these needs in a positive social interaction. Patients know (or soon learn) what needs are legitimate and do their utmost to remain within acceptable confines. They know whom they need, now and in the future. For example, they need and want a positive relationship with the nurse, not just to be liked, to assure continuity of nursing, and gentle handling, but it is human nature to want to feel comfortable with people performing intimate nursing in the private domain of one’s home. Patients are dependent and vulnerable and therefore even more susceptible to society’s cultural norms which keep people confined to their stereotyped roles.
The sick role

As the previous chapter Patients’ Voices and prior discussion on public images and cultural norms reveals, patients are generally compliant because they have needs, because they want a pleasant relationship (they don’t want to feel like an object or negated as a worthless, obstructive person), because they want to stay at home and, in addition, because compliance is the expected behaviour of a patient in our society.

Society and culture reinforce compliance as patients learn the consequences of non-compliance. The value laden language of compliance expresses the need to control what is happening, from an assumption that the medical paradigm (represented by doctors and nurses who deliver the service) know best. The term compliance conveys the type of behaviour a patient ought to display to be accepted within health culture, which is, to conform to the sick role. Everyday living is about informal relationships and expectations - you either meet the cultural norm or you are ostracised (Carrington, 1998).

Sociological writings such as those by Germov (1998), Lupton (1994), Palmer and Short (1989) and Roach Anleu (1991), describe the cultural pattern of the sick role, which dictates how a sick individual is expected to act and be treated. The four central elements, (drawn from the framework described by Talcott Parsons (1951) described in Roach Anleu, 1991, pp.105-132) are:
1. the exemption from performing usual social role;
2. the sick person is not held responsible for their condition;
3. its legitimacy depends on seeking medical assistance, and
4. the sick person may acquire an additional role, that of the patient.

Lorber (1975, p.214) adds “... submission to professional authority, enforced cooperation, and depersonalised status” are imposed norms on the in-patient. In this inquiry, district nursing carries connotations of in-patient care as the home becomes an extension of the hospital environment.

Nurses

The public imagery of nurses is comparative with religious orders and notions of vocational giving of the self with unmitigated dedication. Nurses in this study hold true to the dominant public image of nurses who are seen to be trained in institutions, they have a job to do, have been trained to focus on the tasks, to be organised, efficient and to complete these tasks competently in the given time. The district
nurses work independently and with autonomy, yet there is a knowing (at another level of consciousness) by the public, the patient and nurses, that the medical profession shapes nursing practice and that the image of practicing with initiative is really an image of good nurses following doctors orders.

Nursing deals with the human experience of dysfunction, referred to as illness (Benner, 1985, p.1). The stereotypical patient passively accepts, with admiration and gratitude, nursing assistance. Nurses assist patients with basic nursing care and perform technical procedures, as ordered by the doctor, whilst maintaining and managing the environment efficiently. A nurse may appreciate the individuality of patients’ needs, but knows these must be compromised by the institution’s framework of practice and the consistent need to allocate scarce resources. The nurse is trained to know (sub-consciously) to determine normative needs (Bradshaw, 1972) and to meet these efficiently. Like doctors, they too know what is best - nursing is performed quickly and smoothly when the patient accepts the regime. The patient is talked with, and generally they comply (as expected).

**Patterns of Common Understandings**

Now that public images which also inadvertently become cultural norms, have been explored, it is timely to consider the relationship between the domains of people, culture and environment in the context of health culture. These domains are integrated

... each part necessary to understand the others, each affecting the others in complex ways, and all parts contributing to a social system that has meaning only in so far as all the components are described together, simultaneously, and as a unity (Altman & Chemers, 1980, p.10-11).

This section will now explore people, culture and environment as a unified whole. Society imposes patterns of common understandings upon the individual which become normative expectations and guide behaviour. These are cultural patterns, the taken-for-granted, but powerfully influential, understandings and codes which are learned and shared by members of the group (Merrill, 1969; Peacock, 1986), and these have been described for the community, patients, the sick-role, and nurses. The discussion now layers the norms of health culture in society, against the notions of time and space, as the narratives in the previous chapters consistently reveal time and space as attributes which construct the cultural norms for patients who receive district nursing.
The discussion begins with the commonly accepted image of a patient, where the norms imply that being sick is a minor deviation from normality (which is wellness). This is acceptable so long as the ill person behaves (and responds) according to the sick role; that is, in accord with society’s normative expectation. A person who manifestly accepts benevolence and compliance to a prescribed and dictated regime, will aid their own recovery.

**Time and space as attributes shaping health culture**

Dominant medical knowledge embedded with curative notions within prescribed regimes (time), determines the cultural norms for a person who is unwell. The cultural norm is reinforced as the person, now a patient, moves through (spaces) from the community, to the hospital, to the home. The patient who returns home unwell, or who has not recuperated as expected, has swayed from the cultural norm and, as a consequence, the very sense of self comes into question. Do they choose to remain unwell? Do they benefit from the sick role? They seem to be enjoying the attention! They ought to do more for themselves and be positive.

The sick role model, grounded in the biomedical model of illness, raises discursive notions when patients do not necessarily have the power to conform with the normative expectation of returning to wellness within prescribed time frames. The cultural norm becomes a generalisation applied to all who become ill and need medical and nursing assistance and/or exemption from normal socially defined roles.

When a person’s condition is legitimised by their receiving nursing in the home, time and space are integrated. Nursing occurs in private homes (space) and patients’ days are structured around the nurse coming (time). The majority of participating patients are categorised as ‘chronic’ as they are experiencing chronic, degenerative and malignant conditions necessitating the need for ongoing nursing. In addition, as a consequence of lengthy time frames, these patients are in their home environments rather than in public spaces of hospitals, where illness usually takes place.

Patients live in their homes in the community. Uniforms, an air of efficiency, insignia on nurses’ cars, all explicitly remove anonymity from the private domain of the patient. Nurses have a mode of access by unspoken arrangement. The nurse opens the door, calling out a greeting, and enters the home, moving to where the patient will be. The mode of entry into private territory has been altered and so has the normal social behaviour. Many patients were inevitably ready and waiting - only those who were unaware of reality and therefore of cultural norms, such as Maggie,
or those who were paralysed or very immobile and had no option, lay waiting. Other space intrusions included the use of an area specifically by the nurses which was maintained by the nurses, and intrusions on others in the family whose privacy in their home is reduced when the nurses are in the home.

The time and predictability of the nurse’s arrival gave shape to patients’ days. Nurses talked about nursing time, travel time, the time to provide nursing, lack of time, rationing time as a scarce resource; alongside mannerisms that convey the need to hurry and images of efficiency. Patients are exposed to nursing talk and body language, and in this way, nurses, unwittingly, but nonetheless, effectively, convey their needs and concerns to patients. The common norm or pattern of the nurse-patient interaction is set in shape.

Chronic illness is rarely curable (if it has been diagnosed) and whilst a patient’s symptoms and need for nursing may fluctuate, rarely is there an end to the illness experience in sight. Patients with chronic conditions or impairments, who are not ageing or willing to accept a passive subservient life, grieve for lost lives. Their experience is complicated by the new framework into which they need to fit to receive care and continuing social legitimacy, the rules they have to learn and accept (similar to being a good patient in hospital) now transfer across to their personal homes and bodies. In addition, chronicity meant this will go on and on (endless time and endless need for personal care in personal space).

Space also crosses domains. The spaces that construct normative culture begin with community culture which gives meaning to the patterns of behaviour and experiences that are regarded as normal. It moves to the space of hospitals, to nurses’ space, patients’ space in nursing time, patients’ space for nursing to occur (in the home), the recognition of private space, controlling access to private space, the movement of nursing into private space, and finally the invasive notions of performing intimate needs on personal bodies in private space.

These patients (who participated in the study) had chosen their space and valued being able to receive nursing at home, whilst this positive experience was tempered by the level of dependency for personal body needs, the impact on their sense of self and previous lifestyles, and the level to which routines stifled their lives. These patients therefore experienced varying degrees of loss of control in their homes (private space), and a loss of the normal ability to manage their privacy (personal space and private bodies). Whilst the home and body are normally personal private space over which an individual has control (Altman and Chemers, 1980), this was no
longer the case. Loss of privacy and control of physical and personal environments, as well as ongoing illness, were continual deviations from the cultural norm. The greater the deviation from normal patterns, from the sick role (time) and sickness environments (space), the more patients moved to the margins of society. Cultural norms are out of participants’ control, yet breaches of the norms shape the experience of illness and being nursed.

These unquestioned dimensions of time and space give shape to the illness experience and a certain meaning to their experience of being nursed. For example, the participants in this study rarely fitted into the accepted sick role due to the chronic nature of their illness. In accord with patients’ subjective realities and according to diagnosis from the biomedical model, these conditions are not within the patients’ control. Despite this, the patients breach cultural norms, especially those of time and space.

**Personal places, spaces and nursing**

Homes are traditionally private space, yet the fieldwork illustrated that returning home for continuing care did not imply a return to one’s private domain. In district nursing, the home is an extension of the hospital as the space for ongoing treatment. The home is adapted so nursing actions can be carried out on an ongoing basis.

The home is a territorial base and a place of privacy that is essential to our well-being, as is the ability to regulate our privacy (Altman & Chemers, 1980). As previously noted, patients valued being at home and, whilst nursing impacts on the privacy that is normally conferred on one’s private domain, this was accepted as the cultural norm. Additionally, being nursed in the home is less invasive and, therefore preferable, to hospital or nursing-home environments where notions of privacy are much sparser. Regardless of these accepted compromises, when looking at a person’s experiences of illness and how deviations from time and space give meaning to the experience, it must be remembered that the home is personal space. The home is therefore important to a person’s well-being and any loss of control has implications for self-esteem and self-identity, which may unwittingly affront the psychological well-being of a patient.

Similarly, the narratives in the study conveyed the notion that (in general) the home was much more than shelter. The relationship between the patient and the home tells much about how a person feels about their home environment, which is entwined with a person’s sense of self.
Tom, for example was grateful for his space. He lived in a hostel, in a small room with a narrow window, a bed, and his old familiar bedspread (he remarked with a grin), one chair and three feet of floor space. Scotty had been born in the home in which he lived, oblivious to the stale odours, dirt and rubbish that collected. He had a strong sense of self and was not concerned what others thought. Other homes where spotless. One patient confided that they arranged for the cleaning to be completed (by home help) before the nurse was due to arrive.

In contrast, Wyn always took the nurses to one particular area to perform the technical procedure required. She appeared to live in comfort yet constantly lamented the size of the home, the cost of upkeep and a sense of loneliness. Finally (in interview) I asked why she stayed. She took me to the door of another room where I had never been. Wyn explained she now lived a lonely life, grieving for her husband who had died suddenly the year before. It was their living room - he had died and she still needed to be there. Wyn coped with her grief by keeping their space sacred.

Each patient’s story adds further dimensions, illustrating the integration of meaning between patients and their homes.

The home maintains a person’s connection with mundane life patterns, families, friends, and possessions (Liaschenko, 1994) but alters personal boundaries and private territory. Most patients actively chose the home environment and therefore, by default, invited the nurse into the home. It may be said that the nurse was a guest in the home but the nurse inevitably led the interaction, soliciting what was required of a patient. Nurses were in a dominant position. A stranger in control in a person’s home altered the normal dynamics, but patients accepted this. The pleasure of being in their home overrode normal issues of privacy, whilst in addition, it is the norm for the nurse to lead a patient-nurse interaction. Even patients who felt very compromised accepted nurses ‘moving’ into the home. The meaning for these patients was relative, as they felt less compromised in their home environment, with a limited number of nurses, than in a hospital environment.

**Private Spaces**

The home now becomes an environment that reinforces the cultural norms of the helping professions. Reinforcing occurs innately within practice, simply through comments, body language and the efficient manner of nurses which shape the interaction, implying the helping profession knows best.
Nursing actions are performed on private bodies, invading all notions, and often unacknowledged attitudes, of personal space at the most intimate level. Personal space is an invisible boundary around the body where an intruder may not enter; yet nurses enter the close intimate zone of 0-6 inches (Altman & Chemers, 1980) whilst performing nursing actions. This closeness is accepted by patients because they have needs. What our culture regards as an unacceptable breach of private body space is legitimate when it is performed by nurses.

Personal acts and where these acts occur are also determined by culture. Personal body acts take place in the privacy of one’s home; specifically, the bathroom or the bedroom. District nursing enables the patient to stay within the culturally constructed norms of society - although intimate procedures may have to be performed by others, this occurs within the confines of the patient’s home. Like so many issues in nursing, actions tend to breach society’s cultural norms, though to some extent they are legitimised as they are performed by nurses, and normalisation is strengthened for the patient when the nursing occurs in the privacy of their home. Concurrently, the nuances of nursing language (such as the term basic nursing care) cover a multitude of nursing actions that maintain privacy as acts of nursing are silenced by the cover term.

Nursing also moves beyond personal space and invades a person’s physical being. What nurses do cannot be public knowledge when it is beyond the boundaries of our cultural norms and invades a person’s sense of self and their actual being. Some patients attempt to be in control and lead the nurses. Some nurses accept this as reasonable, often referring to how they would probably react in a similar way if they were in the patient’s position. Others react with disdain, having lost control of their work schedule. The nurses who react with contempt are used to being in control. They expect to lead the nursing interaction, insensitive to their invasion of the patient’s personal space and privacy.

**Dealing with invasive nursing interactions**

Being dependent on another breaches the cultural norm of independence; it breaches a patient’s ability to regulate their own privacy, and if they are ‘chronic’ they breach the cultural norm as they have not returned to health. Dependence risks patients’ sense of self. Independence is lost at many levels, beginning with the notion of others controlling one’s health and then controlling subsequent behaviour in accord with prescribed regimes. The patient becomes powerless as they enter into a new environment where their sense of self is dependent upon learning and, passively complying with unexplained, predetermined rules, routines and expectations of
health care institutions and health culture. Similarly, patients lose their connections with normal life patterns as they are separated from family and friends. They lose control over their own time, their own rhythm of activities and their own decision making (Coser, 1962; Liaschenko, 1994).

Patients who were struggling with the sense of helplessness expressed a desire for familiar nurses, who knew them and how things needed to be done. These patients sought to limit the nurses to those whom they felt comfortable with, explaining that nurses who knew and understood their predicament were less likely to cause any injury because they respected their requests. This, in turn, enabled them to reclaim a sense of self and begin to deal with other important issues in their life.

Fieldnotes draw on a patient’s comments:

It’s different - it’s your body, your excreta and your feelings in their control. You fear being talked about, you fear not being believed, you wish your body was in your control and you think of the things you feel you need. A shower every day ... your nails trimmed, even filed, your ears cleaned, someone to hear how difficult it is to accept the new degenerated you......let alone have other people do these things for you. It’s their job......they assure us.

My personal response to observing this interaction was professionally confronting and I commented in the reflective fieldnotes:

Did they hear the helplessness? When one has no control left in their life, can we expect patients to negotiate as their body is yet again whisked on to a commode chair, as they partake in thought only?

The fieldwork revealed how nurses and patients dealt with invasive nursing procedures. Some would detach themselves from the reality of being there, whilst alternatively, some chose to chatter about trivia as though this interaction was not occurring. This had a distancing effect from the reality of being a nurse performing invasive procedures on another’s body, or as a patient who was necessarily allowing their personal body to be invaded. The coping mechanism or acceptance depended on the relationship between the nurse and patient, therefore every interaction was different.

The nurses who knew and got on with those patients who were physically dependent tended to be allocated, or allocated themselves, to provide for these patients. This was illustrated in Raewyn’s narrative, where the nurses tended to include Raewyn in the conversation. Raewyn expressed an appreciation of being included in a discussion about something else, as then she was less conscious of her body (so long
as it was the familiar nurses who knew the routine and how she liked her body dealt with. In addition, it added something to the day and time went quicker. Other patients explained “... generally the nurse just gets on with the job”, enhancing a sense of normality and decreasing the invasiveness; whilst further discussion revealed it was the familiar nurses whom they knew and respected. In contrast, during the interaction where Bron did not respect the nurse, the atmosphere was tense, as Bron pre-empted every move. She needed to ensure that her own safety and personhood remained intact, but at the same time, this attention to every move enhanced the consciousness of what was occurring and raised an awareness of the invasiveness of the interaction.

**What was private became routine, a non-thing**

Each nurse had their individual manner which gave shape to the ensuing interaction. Occasionally a nurse may seek patients’ cues, but generally they routinely did what needed to be done. Basic nursing care is about mundane personal care, personal bodies being handled by others, sometimes many others. Basic nursing care included intimate bodily procedures such as undressing, bowel treatment, changing urinary catheters, showering, washing, drying, listening, supporting and dressing. To get washed was a routine - organised, carried out and controlled by others, followed by many more invasive interactions. What was private became routine, a non-thing. Just when patients felt they knew the nurse, the routine and the implicit rules, the allocated areas changed, or perhaps their primary nurse was on afternoon shift and another nurse visited. Primary nursing underpinned practice, but it was a fractured reality. Some patients enjoyed different faces coming into the home, but those patients who were dependent for intimate bodily care preferred the same nurse, not just because they each knew the routine but for their own safety.

**The consequences of loss of privacy**

When patients lost the notion of the home as private territory, along with the ability to control their privacy and private bodies, their sense of self was injured. Altman and Chemers note that all cultures have behavioural mechanisms to regulate their privacy as a cultural norm. Privacy regulation is about being able to make choices and manage one’s own social interaction.

By regulating our openness/closedness, or accessibility/inaccessibility to others, we can manage our social contacts with others in accordance with our personal desires, the intimacy of our relationships, and situational circumstances (Altman & Chemers, 1980, p.81).
Alternatively, the inability to regulate one’s personal and environmental privacy, and being frequently subject to unpleasant circumstances, has implications for a patients’ self-worth which frequently resulted in giving up to learned helplessness (Altman & Chemers, 1980). Littlewood (1991) also pursues this concern, noting that if the boundaries between ourselves and the outside world breakdown, we find it profoundly disturbing. It is a breach of the most fundamental level of personal privacy and one’s control over this privacy, thus violating our intrinsic sense of self. In addition, Ong (1991) also notes that a patient’s sense of self is injured when nursing and medical actions negate their values, their experience and the meaning they attach to it. For example, MR knew she was summed up, compartmentalised and stereotyped three times a day, as she was handed-over by people who did not know her, to people who did not know her (Fassett & Gallagher, 1998). When a person feels they are no longer accepted as themselves, that their personhood no longer matters, their sense of self is lost.

In this way the patient’s sense of self is reliant on acceptance and respect from the medical system and specifically from the nurses who are the visual face of the health care system. Each patient’s attitude and their reliance on nursing varied depending on the personality of the patient, the impact of the illness on their lifestyle, their underpinning belief system, the meaning they attach to the experience, their support system; and the attitudes towards them and their illness experience from nurses, family and significant others. If a patient feels demeaned this, in turn, limits the scope of nursing to mere physical procedures.

**Deviation from Time**

Commonly used terms such as acute, chronic, impairment, disability and deviance are labels assigned by nurses and nursing services to patients. These are now defined so that each conveys an accurate meaning within the context of this discussion. It is necessary to understand how a patient is defined, then redefined, to appreciate how time constructs patients’ realities.

As previously noted, nurses deal with illness, which is defined as the individual response to disease (Campbell-Heider & Pollock, 1987). Acute illness is a patient’s response to acute disease which responds to medical treatment within prescribed time frames. Chronic (disease or illness) is defined as “…developing slowly and persisting for a long period of time, often for the remainder of the lifetime of the individual” (Glanze, 1990, p.255). The distinction is that chronic illness has no time frames for a patient’s return to a state where disease is absent. Impairment is a functional loss; whilst to have a disability refers to the physical and social
implications of an impairment that are observable or measurable (Glanze, 1990, p.376). Impairments and disabilities can be temporary or permanent, as the result of birth defects, the disease process or injury. When these functional losses prevent a person participating in normal activities of daily living, nursing language refers to what the patient cannot do as self-care deficits (Orem, 1985).

Using the above definitions, it now becomes clear how the notion of time crosses the domains that influence and give meaning to the illness experience. Aspects of time begin with patient classifications. On entering the district nursing service patients have a predetermined medical diagnosis which is added to as they receive a nursing classification, such as acute or chronic, which, in effect, are indicators of time related to the patient’s diagnosis.

The acute patient has a diagnosis that has a beginning and an end, such as a patient who needs nursing whilst they recover from surgery. A number of chronic patients had multiple sclerosis, and this diagnosis suggests they will need nursing over the long term, as the disease process is degenerative. The classification also indicates the norms a patient will be expected to follow. The acute patient is exempt from their normal social role whilst the chronic patient will be expected to undertake rehabilitation. In this manner, time also moves a patient from the curative paradigm into a self-help paradigm, to rehabilitation programs and the normalisation of lifestyles (Roach Anleu, 1991, p.109). Time reflects the cultural expectations of the biomedical model as acute patients are expected to be passive recipients of expert knowledge, whereas chronic illness and associated disabilities return the responsibility of the body, and the consequences of the illness, back to the individual.

Lives were altered for those patients who experienced chronic illness as the consequence of that illness on their lives, the need for ongoing nursing and an altered position in society. Many of the patients experienced permanency and a high level of dependency for personal body care, alongside the desire to live in their home in the community. These patients were therefore vulnerable as they struggled to maintain a sense of self, compromised by compliance and the need not just to please, but to be seen as a good patient in order to avoid risking their bodies, personhood, and medical and nursing support.

**Chronicity and the sick role**

In order to understand the cultural deviation that accompanies chronic illness, it is timely to revisit Lupton’s (1994) discussion which draws on Talcott Parsons formulation of the sick role. Lupton suggests the social construction of illness
implies that those who develop chronic conditions fail to escape the deviant state of illness or to benefit from the socially sanctioned solution to illness, thereby flouting the third or fourth point of the sick role (Lupton, 1994, p.89). Chronicity therefore implies a failure to seek and comply with medical (expert) knowledge, failure to accept the sick role and be a good patient or that a person remains ill because they benefit from the sick role (such as exemption from their normal social responsibilities). They are labelled as chronic.

Sociological literature notes the limitations of the sick role for certain groups of patients, or more specifically, for certain illnesses. For example, a person who is paralysed does not have the choice of returning to health and therefore the sick role is an inappropriate framework. It also remains problematic as such lack of choice does not confer cultural acceptance; which means the patient with quadriplegia, for example, is not conferred with the cultural legitimacy of the sick role, as would be an acutely ill patient who will return to health. Similarly the sick role is unrealistic in instances such as chronic, degenerative, malignant and disabling conditions or injuries; or when a person makes a choice that is not the cultural norm (Germov, 1998; Roach Anleu, 1991).

However, Germov (1998) suggests that as the sick role directs attention to the doctor-patient relationship. As a result, when the doctor legitimates variations (from health) such as malignant conditions and the ageing process, these people may be accepted as being within the norm. This was clearly illustrated in this study. For example, patients who were receiving palliative care were legitimised by the medical profession and as a consequence, by the nursing profession. Janine’s story was told in *The Nursing Narrative*, and it conveys the legitimacy conferred on her condition and needs, as the doctor-patient relationship conferred her legitimacy into the sick role. Janine had a malignant disease and sought palliative nursing. She had an intense need for medical interventions, she sought and complied with medical advice, hence the time she was ill, the nursing time and finally her death, were not questionable. Her needs were accepted as a priority, as were the meeting of emotional needs and time spent talking and listening (within undisclosed norms that were intuitively known to experienced nurses who were generally allocated palliative care patients).

**The cultural of chronicity**

Those participants in the study, in group two and three (as previously described in Chapter Seven), were insiders to the experience of patienthood. Their disease or illness was legitimised by the medical paradigm, but notions of time and permanency,
with no end in sight, shaped the attitude towards them from society and the medical profession and, in turn, shaped their living reality and the experience of being a patient.

Patients such as Raewyn, Sandra and Bron had chronic, debilitating conditions and permanent impairments such as paralysis. They were experiencing chronic illness and consequently, extensive time frames, no cure, sometimes no diagnosis, a diagnosis that was given too late for any treatment to be effective, or injuries that resulted in permanent impairments which affected their ability to function and care for their personal bodies. They struggled with the experience of illness, with the impact on their sense of self, with grief, loss, hopelessness and powerlessness. They needed nursing to enable their personal bodies to function, to care for these bodies, to avoid further injuries, and to constantly assess these bodies so further problems could be dealt with promptly to prevent complications.

Patients become people with disabilities and chronic illness. They were then classified as being for rehabilitation and normalisation, with a concurrent transfer of the patient’s responsibility for their illness and their needs to the individual, or their immediate family. The inference is that an individual has the choice and ability to manage and be in control of their condition and is (to some extent) responsible for their predicament.

Society, and specifically nurses, might state that the patient has a choice, but do they? Choice implies decisions between options. It suggests that the options offered are entirely beneficial and that the person has the option and will to choose (Cooney, 1988, 1991). Scott points out however that

... in order to choose, one needs to be aware of personal needs, have the mental and spiritual strength to communicate those need and/or alter one’s environment, have support, and communicate to others (1988, p.27).

There was no choice, rather there were two directions: to enter a nursing home and live an institutionalised existence until they eventually died, or to accept nursing services and the expectations which society and nurses elicit from them, as chronic or disabled patients. Their position was predetermined, outside their control, there was no choice. They were outsiders to normative culture having deviated from culturally sanctioned expectations.
The in-between

Whilst it is the cultural norm for acute patients to be passive recipients, the physician’s obligation is to reinforce the patient’s motivations to recover. In chronic illness the corresponding obligation is to reinforce the patient’s motivation to minimise incapacity in order to conform with normal social roles (Roach Anleu, 1991, p.109). However, when a chronically ill patient enters hospital, which tends to be for an ‘acute episode’, passivity is expected. The chronic patient is situated in the acute paradigm where the norm is to hand their body over to expert knowledge and hospital culture. A hospital admission means these patients have to renegotiate (if they have the will and the courage) just what is expected of them, with all the health professionals (given their history, and given that they may be unaware of what has been documented in their history). Bee Rawlinson, a nurse and patient who suffers with Lupus, recently wrote an article seeking to raise nurses’ awareness of what it means to be chronic in an acute setting with given expectations. As Bee explained,

I know people with chronic conditions can become very particular about their treatment, but, take a moment and think what it must be like for them. These are individuals who usually manage their own health at home and have to live with chronic pain, fatigue, malaise, and a myriad of other symptoms (Rawlinson, 1999, p.10).

Labelled as chronic

Labels are a consequence of a condition and patients are not at liberty to refute these circumstances, in fact, in a rather cynical manner, labels legitimate altered body images and social absence that are the consequences of illness or disability. In addition, a label is necessary to access assistance such as nursing.

Labelling is not a benign activity, it is the identification of rule breaking. Roach Anleu (1991, p.33) explains that a labelled person is required to enter the social role appropriate to that label - to undergo certain types of treatment, to modify his or her behaviour in ways seen as therapeutic, perhaps to abandon all other social roles and enter an institution filled with similarly labelled person, such as hospitals, nursing homes and day centres. Cooney argues that to label a person is to deny their individuality, their social identity and the right to self-definition (1991, p.25).

The ill person has deviated from the norm of health, whilst chronicity goes a step further, inferring deviation from the culturally accepted sick role. The attributes of deviance are defined as:
“... a) being different from others; b) one or more dimensions which are viewed as significant by others, and c) this difference must be negatively valued” (Wolfensberger, 1980, p.10).

In discussing normalisation, Wolfensberger explains that society tends to group devalued people into cohesive role images, such as the sick person;

[T]he medical model is extremely powerful ... the devalued person, or person with a devalued condition is cast as ill, sick, diseased, becomes a “patient”, who is “diagnosed” and gets a “prescription” for “treatment” with some “therapy” administered in “doses” in “clinics” “hospitals” and “treatment rooms” by personnel who are called “doctors”, “nurses”, “aides”, “therapists”, who open “charts” on him/her, “staff” him/her, the outcome being “prognosticated”, “cure”, being the hope, and “chronicity” resulting in despair and withdrawal on the part of the medical service culture (Wolfensberger, 1980, p.12).

Failing to adapt to the socially sanctioned solution to illness results in a permanent deviation from society’s norms. Chronically ill or disabled patients must learn to adapt, to manage their illness and accept impaired functioning as an everyday state rather than a temporary deviation from the norm. Traditionally, over the past few decades in Australia, acute treatment has taken place in the hospital environment under the medical gaze (whether the gaze be by doctors or nurses, it was focused on disease). Due to complexities (such as money) framed in terms of choice, patients are now allowed home with a district nursing referral.

Assistance is legitimised, as these patients are handed back their bodies and the responsibility of their illness, moved on to notions of self-help, families being trained to provide for them, rehabilitation and normalisation. Family members are now carers, trained to change catheters condoms, urinary bags, supra-pubic catheters; to transfer their patient who may be paralysed, to give intramuscular injections, and learn the intricacies of providing personal body care. The reality was even harsher as patients were trained to give their own suppositories with suppository guns if this could be physically achieved. In addition, rehabilitation programs and normalisation had far reaching meaning for patients.

The meeting of personal body care by family members was especially unpleasant for younger patients who were no longer children cared for by parents. Likewise, teenagers, adolescents and middle-aged people had to be cared for in this context by family members, who were frequently their parents. As the time we spent together increased, patients spoke about a loss of personal privacy and having to be compliant with parents to have their needs met comfortably. Similarly, parents expressed concern at having to do this to their children who were now adults.
They felt they were breaching the person’s normal privacy and dignity. They did not choose to, but this is how health culture deems it must be. The only other option (which one could not suggest was a real choice) was institutionalisation in an aged care facility.

Sandra (and those whom she represents) had originally been acutely ill. Overtime she developed impairments that became permanent. Eventually she was diagnosed as having the disease multiple sclerosis (MS). MS is a chronic, degenerative disease and the impairments created self-care deficits and permanent disabilities. As a consequence she is dependent for many activities of daily living. She is classified (labelled) as ‘chronic’ and ‘disabled’. She is dependent and vulnerable yet she chooses to live at home and, in general, finds great pleasure in her relationship with the nurses, to whom she expresses eternal gratitude.

Strauss 1975, (cited in Walker, 1999, p.10) provides an encompassing definition of chronic illness as:

All impairments or deviations from the normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alterations, require special training of the patient for rehabilitation, may be expected to last, to require a long period of supervision, observation or care.

As an insider, I found the assumption that chronic patients will be subjected to re-training through rehabilitation programs to normalise their lives rather arrogant. It is a definition which may aid government or medical categorisation, but diminishes any concept that this process is in reference to people. It is worthy of consideration, however, as it captures the cultural norms and expectations for a patient who is labelled as chronic.

Rehabilitation

As previously explained, the social sanction of acute illness is not available to chronic patients, but Strauss’s definition does aid in coming to know the pathway, the cultural norm pre-determined by the social construction of health and illness, that moves a patient from the acute to the chronic or disabled phase of illness.

The following patient’s comment highlights their felt obligations, as opposed to choice or perceived benefit.
I sort of felt it was a bit of a waste of time because I have done these sort of things before ... but they always suggest what you should do and I felt I couldn’t really have them suggesting it every time and me not following through. So I just felt that I had to ... I couldn’t always have them looking for something that would help me, if I wouldn’t perhaps meet them half way.

If a patient declines this step, they continue to deviate from the norm, not helping themselves, choosing to live constrained by injured bodies. Some patients found rehabilitation beneficial whilst others did not, but the dilemma is that patients really have no choice, even about the content of their rehabilitation program. For example, Liz and Rosalind emphasise the normative content of these programs, which consequently failed to address patients’ specific needs.

Liz wrote, “There was not enough emphasis on practical skills and personal care but too much emphasis on sport and walking and competitive attitudes.” Rosalind felt there was too much emphasis on the physical achievement, for example, walking with callipers. She stated “I was pushed too hard in physiotherapy when I was exhausted” (cited in Morris, 1989, p.27).

In *The Nursing Narrative*, Vera’s story was told as she returned home after a recent stroke. Recall that, despite Vera’s age and obvious physical struggle, the rehabilitation physiotherapist had suggested she try to undertake more hygiene and dressing activities herself. Vera had responded to the physiotherapist and avoided this normative expectation, but she felt guilty and concerned about being seen as lazy, undeserving, or not trying. The point was that whilst cultural norms direct a patient towards rehabilitation and normalisation, in this instance, the cultural norm overrode and took no account of Vera’s illness experience. It was the health professional’s objective, but it was an outsider’s objective that lacked recognition of the person who has become a patient and of the fact that what Vera felt (but would not express to an outsider) was realistic, given her illness, age and circumstances. The discussion also illustrates how we do not understand the power of culture and the subconscious level at which culture shapes our interactions and expectations, or shapes feelings of guilt.

**Moving out of the Medical Paradigm**

Conversely, Vanderfield offers a positive perspective, explaining that

Rehabilitation is about restoring and relearning abilities or finding new ways of doing everyday activities ... [and] ... the more we know about rehabilitation nursing practices, the better we can support people to regain control over their lives (1999, p.7).
Vanderfield removes these patients from the medical paradigm, to focus on empowerment and what may be possible. This statement, with notions of support and regaining control, avoids notions of health professionals being in control, whilst also alluding to a positive focus of patients and health professionals working together.

**The Emic and Etic Perspectives**

Both patients and nurses participate in the social construction of health and illness, but that is not to presume that this was always the case, that there was a conscious choice, or that there was any choice for either party. The process is representative of the generalised cultural norm, of the etic perspective. In contrast, nurses and patients seek and negotiate their way through the system as individuals from the emic perspective. The cultural norm conflicts with nurses who practice from a humanistic base, with respect for persons, and who accept that the patient should participate as a partner in their experience of being nursed. Similarly, some patients have a strong sense of self, or feel so angry at being trapped that they found ways to resist or manipulate the system. Abercrombie Hill and Turner (1980) suggest that control by the dominant is constrained by interdependence, as is the case between nurses and patients, that results in a merging between common culture and the dominant ideology.

In moving back from generalisations to individual emic experiences, the ethnographic description is a reminder that no day is typical, nor is any nurse or patient. Nurses are individuals who nurse for different reasons, consequently, impacting on the way they go about their nursing. Patients have diverse expectations and choose to be treated in different ways. Some willingly follow the norms, others accept this position simply to get by, some are frustrated with constraints and expectations, whilst others, like Vera, find a way of resisting the expectations. Illness impacts on lives, personalities and ways of being. There are classifications of needs that have unique implications and values that a patient sets store to, which may be different to the needs the nurse is funded to meet or even emotionally able to meet. Simply, there are types of nurses, patients, and needs, and many versions of reality. Likewise, returning from the general to the particular, draws attention to the vastly different meaning nurses and patients attach to the nursing interaction.
Summary

By overlaying the cultures of nursing and patients, the level to which the patient’s experience is shaped by cultural norms is starkly revealed. Uncomfortably so. The norms of time and space both construct normative culture, whilst deviations from the norm then construct the ongoing experience of being a patient. Time reveals categories of illness, from acute through to chronic, with corresponding normative expectations and predetermined pathways. The acute patient hands their self over to the health care professionals, whilst if they do not return to wellness within prescribed time frames, regardless of underlying pathology, the responsibility for managing their illness is handed back to the individual. In addition to these predetermined cultural norms, strong meanings are attached to notions of space. These include the spaces where health care takes places, the invasion of personal space in private homes and, finally, the invasion of private bodies. Together, time and space shape the pathway a patient is expected to follow, the meaning of the experience of illness and, as a consequence, the patient’s sense of self.

This chapter has illustrated that nurses are active participants in the cultural construction of a patient, which is a dehumanising process, despite the fact that nurses believe they work from a humanistic theoretical base. That is not to say that nurses do not hold and value humanism, but that the shaping of normative culture is subconscious. The shape of practice is predetermined and it is the cultural norm for nurses to lead the patient through the layers of health culture. The meeting of nurses and patients revealed more than people accepting predetermined roles; these roles are social constructs of acceptable behaviour and as participants we need to understand the construction of the roles and interactions in which we participate. Only when we understand the culture in which we participate is there any possibility of change.
This chapter illustrates the social construction of the illness experience. The discussion begins with an exploration of how and why the biomedical model of medicine has become the dominant norm in our society, shaping and giving meaning to the norms of health, wellness, and health culture. It then looks at the experience of becoming a patient; whilst the third phase looks at the social construction of patients, specifically drawing out the ambiguities between professionals, cultural norms and patients.

Being part of society shapes each individual’s experience as a patient. People (and therefore patients) come to know, albeit at a subconscious level, what our culture regards as health and illness, who has the right to define these, and the expected norms of behaviour.

The narratives so far have illustrated that the medical profession has the right to define illness; nurses have illustrated how they convey to the patient what are legitimate needs, whilst in some instances, negotiating illegitimate needs. Nurses have demonstrated the expected norms of behaviour within the nursing interaction and the sick role, whilst the medical profession demonstrated that chronic patients are expected to relinquish the sick role and resume self-responsibility whilst remaining compliant with the medical and nursing paradigms. The patients’ voices have been self-revealing with regard to their experiences as recipients of medical and nursing knowledge, where compliance and passivity are necessary attributes of conferred legitimacy. These patients had given up on cure, but they still wished to maintain a semblance of their chosen lifestyle, to feel comfortable, even to enjoy their relationship with nurses, whilst having their nursing needs met. These are not mere wishes. Each is a basic human need that must be met if patients are to maintain their personal integrity.
This final layer of the ethnography seeks to explore the big picture of the cultural construction of being a patient. It looks at the shaping of health culture, the cultural experience of becoming a patient and the contradictions between the professions and the patients. The aim is to gain an insider’s perspective of the cultural experience of being a patient, to understand why patients adopt a submissive, compliant position; and why patients must risk their sense of self to have nursing needs met, to have a comfortable interpersonal nursing relationship, and to maintain some resemblance of choice within their compromised lives.

**Medical Cosmology and the Shaping of Health Culture**

To begin to understand what it means to be a patient it is necessary to appreciate the cultural dimensions of disease, illness and the medicalisation of people’s lives. An historical perspective provides insight into the evolution of medical dominance. This background enhances an understanding of our current day experience, illustrating why the biomedical model and the medical paradigm have become so dominant, shaping society’s cultural definition of health, wellness and permeating the cultural norms of society, nursing and patients.

This section draws heavily on the writings of Jewson (1976), in conjunction with Dingwall, Rafferty and Webster (1988) and Roach Anleu (1991). These writings enabled an appreciation of the medical paradigm and why this has been, and continues to be so powerful in shaping peoples’ experiences throughout the many areas of health culture. This literature deals with the evolving mode of production of medical knowledge and how this has shaped the experience of people who seek medical advice and subsequently receive nursing care or attention. In particular, an historical perspective of medical cosmology has added depth and breadth to my own appreciation of the dynamic interdependence between doctors, nurses, patients and society. Throughout the fieldwork I had become increasingly conscious of the medical construction of health, illness and nursing but, initially, could not understand why this was so deeply ingrained in society and culture.

**The evolution of medical cosmology**

‘Cosmology’ is the term used to capture the essential nature of universal medical discourse about ways of seeing and making sense of the world, of what we know and what it is possible to know (Jewson, 1976, p.224-225). In coming to understand the changing norms of health and illness, Jewson describes the disappearance of the sick person along with the change from a person orientated cosmology to an object orientated cosmology, associated with the changing mode of the production of medical knowledge.
Contemporary anthropological and sociological literature, such as Chrisman (1982), Dingwall et al. (1988), Jewson (1976), Lupton (1994) and Twaddle (1981), discuss the historical role of medicine as interpreting signs of illness based on the sick person’s subjective self report. Historically, health was a person’s subjective reality. However, this evolved to an object orientated reality, corresponding with the evolving relationship between medical professionals, people with an illness, the rise in scientific knowledge and a direct and powerful relationship between science and medicine. The evolving nature of science, the industrial revolution and a patriarchal society, shaped the normative culture of sickness, from an integrated relationship between a doctor and patient to the dominance of medical knowledge. The consequence has been domination by the medical profession which, in turn, shapes cultural definitions of health, patients’ experiences and the practice of other health care workers.

In order to understand how cultural meaning evolved, it is necessary to step back to review medical anthropology and sociology. From the literature of Dingwall et al. (1988), Jewson (1976), Lupton (1994), and Taylor (1979), four clearly identifiable stages become evident.

1. **Bedside medicine**

The first phase is described by Jewson as Bedside Medicine (1976, p.227). This was an integrated process between the doctor and the sick person, existing up to and around 1770, prior to the industrial revolution.

[Disease] ... was defined in terms of its external and subjective manifestations [and accordingly] ... diagnosis was founded upon the patient’s self report of the course of his illness (Jewson, 1976, p.228).

This phase specifically draws on the equality between patient and doctor as the patient’s observable and subjective reality was central to medical knowledge.

2. **Hospital medicine**

The second phase is referred to as Hospital Medicine (Jewson, 1976, p.229). This phase occurred in conjunction with the changing mode of production of medical knowledge. Medical knowledge was now produced in hospitals where the unique qualities of the ‘whole person’ were replaced by a collection of synchronised organs.
As Jewson explains, the

... raw materials of medical theorising now became the innumerable morbid events, occurring within the gross anatomical structures, which presented themselves to the clinical gaze on crowded wards (1976, p.229).

Jewson (1976) and Dingwall et al. (1988) note that this phase began in France in 1789 when French revolutionaries opened hospitals under state ownership. Apparently, before the revolution, hospitals had been benevolent and charitable organisations, heavily influenced by the Catholic doctrine. During the following decades of the nineteenth century, with the French hospitals in lay control, experiments were conducted without the restraints of Catholic moral teaching. The literature describes doctors having access to large numbers of ‘poor’ people, on whom they practised objective, experimental medicine (Hospital Medicine) as clinicians moved their concern from prognosis and therapy to diagnosis based on clinical observation (Dingwall et al., 1988, p.20-22).

3. Laboratory medicine

The third phase was referred to as Laboratory Medicine (Jewson, 1976, p.230). The public hospital system in France, at this time, also enabled doctors to freely access corpses for dissection, thus paving the way for advances in human biology (Dingwall et al, 1988). Jewson (1976, p.230), however, asserts this phase began in the mid-nineteenth century German University system. Nevertheless, the changed mode of medical knowledge was synonymous. Clinicians now asserted that observational anatomy didn’t explain the causes of disease. They built upon experimental physiology, with clinical diagnosis made by pathological tests, underpinned by the cell as the fundamental unit of life and therefore the focus of disease (Jewson, 1976, p.230). Laboratory Medicine, commonly referred to as the biomedical model, converted the subject to an object, as disease was grounded in scientific objectifiable observations that were empirically demonstrative.

4. Health as a negative value

The entrenchment of medical domination continued through the later stages of the twentieth century as a consequence of constantly advancing medical technology and medical research (Illich, 1976, 1977; Taylor, 1979). This led to a fourth stage, that is the dominant mode of medical knowledge at this current time; that is, through the later stages of the twentieth century. The domination of medicine has become so embedded in our way of life, that health and wellness are measured by the absence of
disease, confirmed by successive negative tests. Normal life patterns, from child birth through to menopause and the process of ageing, have become medical issues. In addition, the subjective experience of symptoms or illness is only accepted by society as legitimate if this is conferred by the medical profession. People consult the doctor for regular tests, the medical profession defines health problems and how they should be managed, and the legitimacy of being sick is dependent on seeking medical advice. Medical legitimacy then converts the person to a patient, who is now obliged to follow prescribed regimes without question. Illness and wellness are medically defined and the biomedical model is reinforced by society as the cultural norm, and perpetuated by society’s organisational structures.

The consequences of change

There are three enduring consequences of evolving medical cosmology that are of significance to this study. The first is the conversion of the sick person from subject to object. The second is the evolution of medical knowledge, the occupational standing of clinicians and the elite status clinicians achieved, based on their occupational role rather than on proven worth. Thirdly, these changes set the current day norms of what it means to be sick, along with expected normative behaviour of the general population in their quest to maintain their health and the expectations on those who experience illness.

The conversion of the sick person from subject to object: As the sick person was progressively converted from an integrated subject to objectifiable data, a person’s subjective reality was no longer of any consequence to medical knowledge. Finally, health has become a negative value that can only be assured (by others) through regular tests to demonstrate the absences of disease (Illich, 1976, 1977; Jewson, 1976; Taylor, 1979).

Elite status: The evolution of medical knowledge, the occupational standing of clinicians and the elite status clinicians achieved, was based on their occupational role rather than proven worth. The medical profession secured occupational, professional, and knowledge elitism, within the broader construction of hospitals and, generally, within society, therefore dictating the cultural norm (Dingwall et al., 1988; Jewson, 1976; Palmer & Short, 1989).

Dominating power in health culture: Finally, the abstract notion of constructing a person into an objectifiable object, referred to as a patient, in conjunction with an elite body of knowledge to which no one else has access or rights, and the acceptance of this form of science by society, explains the domination of the medical
profession as the corner stone of health care culture and, in turn, its impact on the cultural norm of being a patient (Samuelson, 1991).

**Nursing and medicine: An historical perspective**

Thus far, this discussion has explored the evolution of medical domination and the objectification of patients which secured medicine as the dominant occupational, professional, and knowledge cornerstone of health culture. Having established this, it is imperative to understand how the discourse of medical domination impacts on and shapes the norms of health culture, specifically, for those who nurse and are recipients of nursing.

To explore the relationship between nursing and the medical paradigm, it is timely to revisit the historical nurturing role of women and the evolution of nursing, looking back on Chapter Three, *Setting The Context*. Women were historically the nurturers of society, caring for people in lay environments, in the home, their communities, or vocationally within benevolent organisations. This pattern was shaped by English licensing laws which prevented women from the legal right to education and wealth (Summers, 1975; Russell & Schofield, 1986). As a consequence, women were excluded from universities and therefore medical training and practice. In this way the ramifications of history shaped and, arguably, continue to shape, the male dominated institutional nature of medicine and hospitals, and the culturally legitimate role of women in cure and care (Summers, 1975). The evolution of medicine, as the dominant corner stone of health care had repercussions for the division of labour in the care of the sick and in shaping nursing practice (Samuelson, 1991).

According to Dingwall et al. (1988), when doctors returned to England from Paris, they continued the Parisian practice of admitting patients to hospital based on their value for teaching or research. Inevitably with this mode of practice, there was a gap in the continuous observation and the provision of treatment when the doctor was not present and, as a result, some doctors began to improve the education, conditions and status of nurses (who were regarded as housemaids rather than nurses or nurturers). These changes in nursing came about due to the medical evolution and occurred approximately thirty years before the establishment of Nightingale’s school of nursing in 1860 (Dingwall et al., 1988). This information illustrates how and why nursing practice was historically shaped to meet the needs of the medical profession, resulting in a dominant yet integrated relationship between nursing and medicine.
In 1860 the first School of Nursing (in England) was commenced by Florence Nightingale. This form of nursing was transferred to Australia with the arrival of Lucy Osbourne, a Nightingale trained nurse, to commence nurse training as requested by the Governor. Apprentice style nurse training began in institutions, to meet the needs of the institutions and the medical profession. Nurses’ work involved observing and reporting to the doctors, the provision of a clean environment and meeting the needs of the sick (Gwillim, undated).

The implications of medical dominance for nursing

Medical domination continues in current day society. Samuelson notes that the power of biomedical knowledge is the cornerstone in health culture in western healing systems, with nurses in the middle, with service functions, and patients at the bottom as receivers (1991; Jewson, 1976; Palmer & Short, 1989). Whilst nursing is philosophically based in humanism, which places the patient as central to practice, the historical dominance of the medical profession and medical cosmology, where the patient is objectified and the nurse is an extension of the doctor’s hands, continues to shape health culture. In turn, nurses are socialised into medical culture and, as Salvage (1992) argues, the price for acceptance and being part of the team is subordination.

The cultural implications for nursing has meant that, as a broad generalisation, society sees nurses as handmaidens for doctors, or as those who can perform tasks for doctors in their absence. The medical profession is perceived as ordering the actions nurses perform; and nursing interventions, outcomes and care are accredited to the medical profession. Returning to the study, fieldnotes sum up the dichotomy.

The district nurse was expected to practice autonomously in people’s homes yet to remain subservient to doctors’ orders or what a particular doctor would have ordered (as there were generally no written orders). This was the cultural norm; patients liked this and doctors expect this. They order the nurse to carry out the wound dressing (as necessary). Each Friday the doctor then visits the patient at home and looks at the wound. The patient explained the doctor was pleased with the quick wound healing and she (the patient) was very grateful to the doctor. In this instance, the nurses assessed and dressed the wound using nursing knowledge, whilst the doctor visited regularly to make comment and reclaim positive outcomes. In addition, the patient was grateful to the nurses whom she perceived as carrying out the doctor’s orders.

Doctors generally do not appreciate being interrupted (such as the nurse ringing the doctor’s surgery if a patient was unwell or to have orders changed). They expect the
nurse to use their knowledge and act autonomously. The doctor and nurse would liaise in the afternoon, during the surgery break, and the doctor would then change orders, write pathology slips and fill out prescriptions. On numerous occasions nurses acted with autonomy, as exemplified in Maggie’s story, cited from the fieldnotes in *The Nursing Narrative*.

The nurse listened to Maggie’s problem, made an informed decision based on nursing knowledge and the patient’s story, did a urine test, collected a pathology sample, organised plenty of fluids which Maggie could then access and explained to her why this was important. The nurse contacted the doctor’s surgery, left a message and organised a follow up nursing visit that afternoon. The nurses knew the doctor-patient relationship and took this into account in their practice.

Whilst the above incident refers to an acute episode, most of the patients were ageing or had chronic illnesses and/or disabilities and therefore only had a tenuous relationship with doctors. The nurses cared for them and patients expressed a deep appreciation of this. What was not evident, except in reflection, was the manner in which the nurses subtly negotiated through and around the medical profession and cultural norms, to ensure patients were treated and comfortable. In addition, nurses also negotiate around other nurses; for example, the primary nurse may drop in later in personal time, as a friend. This was not a reflection on the other nurse (although in some instances it reflected a tension between different values held by different nurses), but illustrated the depth and meaningfulness of the nurse-patient relationship.

Whilst medical cosmology moved the patient from a subject to an object, the above discussion provides insight into how some nurses discreetly negotiate medical domination and cultural norms, and that this practice, in itself, has become an accepted norm. It is accepted for the very reason that nurses do not obviously flaunt those who are dominant, and in practising in this manner, all parties benefit. The medical profession remains culturally dominant, the patient believes the doctor has guided the nurse’s practice, nurses are able to do what they professionally believe needs to be done, and patients are respected. If, however, a nurse follows dominant cultural norms and doctors orders, the nurse would not be able to take account of the patient as a person, they become an object. Most nurses would agree with Griffin’s statement, that a patient’s needs matter

... because part of the very definition of human being is of someone deserving of respect as being of ultimate worth (1983, p.291).
The implications of medical dominance on society

The prevalence of medical dominance over society is that it has become the cultural norm (a given consensus) to accept and reinforce the power of the medical profession. Medical knowledge diagnoses and treats disease, prescribes associated behaviour and is regarded as having the right to define health (Illich, 1976, 1977; Taylor, 1979). Medical dominance means a person does not need symptoms to seek medical advice. It is the doctor’s prerogative to do a test and pass judgement, and consequentially society actively seeks medical legitimisation of many everyday activities. For example, a person’s absence from their normal activities such as work, exemption from jury duty, purchasing life insurance and pre-employment medicals, must be legitimised through medicalisation. (Do you know if you are well enough to work?)

On an individual level society actively seeks the medicalisation of normal life processes so that, now, wellness is a state confirmed by successive negative tests. People are actively encouraged by public policy, media campaigns and central registries of results (that post reminders when the next test is due) to seek to be diagnosed as healthy (Cooney, 1988, 1991). In a similar rather perverse notion, advertisements and public discourse suggest an individual will be responsible for their ill health (which is inevitable) if they do not partake in tests to confirm normality. It has become a social responsibility and a cultural norm, which, in a cyclic fashion, reinforces itself.

On the other hand, society unquestioningly accepts the advantages of medical dominance, whilst failing to acknowledge the disadvantages, despite the broad body of literature alluding to the dangers of modern medicine. Batt (1994), Cooney (1988, 1991), Taylor (1979) and Illich (1976, 1977) argue that this powerful dominance not only ignores, but results in a sense of powerlessness of individuals and then perpetuates this powerlessness through vulnerability, loss of integrity, and ignoring the humanity of a person.

Whilst people have an expectation that seeking medical advice will result in improved health, a plethora of literature illustrates no correlation between the number of doctors and health (Illich, 1976, 1977; Palmer & Short, 1984; Russell & Schofield 1986; Taylor, 1979). In addition, clinical iatrogenesis which...

... comprises all clinical conditions for which remedies, physicians, or hospitals are the pathogens, or ‘sickening’ agents (Illich, 1976, p.36) [is
widespread]. [The extent of] ... pain, dysfunction, disability, and anguish resulting from technical medical intervention now rival the morbidity due to traffic and industrial accidents and even war-related activities (Illich, 1976, p.35).

Basically these positions highlight the assumed neutrality and good, demonstrating the power of culture.

The question then is, if medicine is so irrelevant to the medical needs of so many and has so many negative implications, why does society seek and confer the rights of the medical elite? Cooney (1991) suggests domination is accepted by society due to an overriding cultural obsession with immortality, perfect bodies and cure.

The participants (as an example of individuals in society) needed to meet the expected norm to access the rights by which society confers entry into the sick role. The study illustrated that, when people had nursing needs, it was crucial to act in accord with the norm to ensure their needs were met now and in the future. In addition, as humans, there is an essential need to enjoy a comfortable relationship with those who meet our health care needs. Patients therefore accept the responsibilities of the sick role, meeting the expected norms of society as a good patient. It is the cultural norm to seek and confer the rights of the medical paradigm, whilst to question the cultural norm breaches compliancy and is risky. Having deviated from normative culture a person becomes responsible for their condition, with the associated risk of being perceived as negligent or deviant and, as a consequence, not necessarily being entitled to the rights conferred by the sick role.

The implications of medical dominance for patients

Medical diagnosis is very meaningful to patients as it shapes the illness experience. People have preconceived beliefs and meaning based on knowledge and myths which they attach to symptoms. When they seek medical advice for these symptoms the diagnosis or non-diagnosis adds a further layer of meaning and, in turn, shapes how a person experiences an illness.

For example, if two people present with similar symptoms, scientific tests may confer one patient has cancer. The other patient may be faced with no diagnosis, which translates as no negatively defined tests. The symptoms may be the same but the experience of illness and the meaning attached to the experience will be very different. The patient who receives a diagnosis will still have the same symptoms, but they will be granted entry into the sick role and offered curative expectations. As
Roach Anleu, explains, “[d]efining symptoms as illness gives people’s conditions legitimacy and reality” (1991, p.114). Their experience is shaped by conferred legitimacy, treatment, and exemption from normal roles. The illness experience of the patient who receives no diagnosis will be very different. In the medical view, they are well, the test was not negative, ‘it is a figment of the imagination’ accompanied by expectations of getting on with life. Regardless of symptoms, they are designated as being well, and continued absence from their normal social obligations or seeking further medical opinions is negatively perceived as malingering or illness behaviour.

In addition, as illustrated in the previous chapter, Patients and Health Culture: Time and Space, the medical paradigm intrinsically fails to address the needs of patients whose condition is not curable. Cure is the hope, whilst chronicity results in withdrawal on the part of medical culture (Wolfensberger, 1980). Patients are handed back their life, expected to come to terms with abandonment by medical notions of cure, to learn to live with their illness and to focus on rehabilitation and normalisation, despite their illness. As the medical profession retreats, patients who experience permanence enter a new prescribed cultural norm, with referrals to other services such as home nursing, rehabilitation programs and day centres.

The participants, as a sample of the population who receive nursing in the home, were rarely regarded as having curable conditions, yet cure remained the dominant norm and the focus of the health care system in which they were participants. As such, the label of ‘chronic’ attached to many of the participants now serves a positive purpose, demonstrating the irrelevance of a purely curative focus for a substantial group of patients. Because of this label they will not be granted the rights to the sick role, and therefore it becomes even more important for them to be compliant with the nurses’ ways, to be good patients, if they wish to be perceived positively by the nurses, as has been shown to be the norm.

The all encompassing reason people in society sought out and passively complied with the medical regime was because it was the norm. These patients have defaulted from the medical norm and they are now compliant with nursing as the norm.

**Linking Doctors, Nurses and Patients**

Whilst the discussion has dealt with the hierarchical shaping of patient’s illness experience by the medical profession, it is timely to move down the medical hierarchy to the relationship between the medical profession, nurses and patients.
After the medical profession, nurses are the next layer in the hierarchy of health professionals. What nurses do has been shown to be historically linked to the needs of doctors and the public image of nursing practice is reflective of this paradigm. Nursing imagery is associated with doctors, hospitals, acute care settings and performing technical tasks in the public domain of health care. Furthermore, nursing has evolved alongside medicine, subject to the expectations of goodness and compliancy with the medical status quo which insidiously reinforces the medical role.

Like nursing, the public imagery of patients is focused on acute illness, the medical paradigm and curative notions. The study and prior discussion on the evolution of medical dominance confirms that the medical paradigm only accommodates a small number of patients, due to the narrow focus on acute illness and cure, yet it determines the norms of health culture. The medical paradigm is the mode of entry into the health care system and predetermines the various pathways of patients according to their condition, the course of their condition and compliance. Helle Samuelson suggests that, as a consequence,

... patients are a truly muted group. They are assigned a passive role in a bureaucratic power structure and caught in a routine they cannot influence (1991, p.200).

**Being a patient and being redefined from the acute paradigm**

When a patient’s condition is deemed as stable, this suggests their health status is no longer improving or benefiting from active medical treatment; or that pathological tests are negative or inconclusive, inferring the absence of disease. Regardless of the patient’s subjective reality, their medical status is subject to redefinition. Nurses or patients are not necessarily conscious of this process, as it is simply the taken-for-granted norm that, at a given point in time, in accord with given circumstances, the medical profession refers the patient to rehabilitation, day service, physiotherapists, occupational therapists and even psychologists. Depending on the patient’s overall condition, their needs, and accessibility to other service providers, the patient will be transferred to a rehabilitation facility or discharged home.

The sick role infers the patient will respond to medical treatment and return to health within prescribed regimes. Redefinition infers the patient has deviated from society’s normative expectations of cure.
On one hand the patient is redefined due to lack of medical progress, then this redefinition is turned around and described in positive terms as progress. It is also a part of the experience of being a patient that is simply not recognised. ‘We’ (in reference to doctors and nurses who are health professionals in the medical paradigm) frame the patient’s experience. One day they are informed, “there is nothing else we can do, but you can go home and begin rehabilitation”. Nursing comments suggest the patient should be pleased to go home, to be able to determine the structure of their day, to escape from a medical regime; but do nurses really think holistically about their patients? If they do, there are many questions they need to answer about the meaning of this experience for a patient.

How does it feel and what does it mean to an ill patient who is dismissed by doctors, when our whole culture is based on believing in the medical paradigm and seeking perfect bodies, health and wellness? What does it mean to be redefined, especially when it only occurs when the patient fails to meet curative notions? How do patients manage to cope, when their subjective reality is one of feeling unwell and loss of function, and they are told to go home? Support will be arranged, (so they say) but what is it like to face an uncertain future and the possibility of ongoing illness?

Redefinition implies that the person who is the patient will be moved through the health care system. As an insider to the world of being a patient, I know the grief and anger that many patients experience when they are informed that they must accept their condition as a daily living reality rather than a passing illness. What does wellness mean to the patient whose illness is no longer deserving of hospital space and further tests, which they were previously expected to passively accept? This reality reflects back to the historical position when patients were admitted to hospital based on their value for teaching or research, as medicine focused on diagnosis rather than prognosis (as in Hospital and Laboratory medicine as described by Jewson, 1976).

For a time the patient is in between. They are usually still being actively treated (or being tested) by doctors and therefore they are expected to accept expert medical knowledge with submissive compliance. In addition patients seek and have been led to expect a diagnosis, treatment and cure. Many patients talked about the struggle of non-diagnosis, or of the notion of being stable and moved on. On one hand these patients have not met the cultural norms as good compliant patients but, in reality, compliance does not confer diagnosis or cure. On a personal level there is grief, anger and frustration or resignation that the medical profession has failed them, or
that their bodies and their condition do not allow them to fit with the status quo.

Most people who feel healthy, can hardly imagine the adaptive tasks that inevitably accompany a chronic disorder, such dependency on others, or living with pain or fear (Ridder, Delpa, Severens and Malch, 1997, p.555).

**Being redefined**

The discussion now looks at the ongoing process of becoming a patient, drawing on personal insider knowledge as a nurse, a patient and as the participating researcher, and with continuous ethnographic analysis, to illustrate the pattern of entry into nursing culture and the framework of nursing practice which gives shapes to the experience of becoming a patient.

When people enter the realm of nursing they have inevitably been subjected to medical culture as the cultural norm in society when a patient deviates from perfect body imagery, experiences symptoms, or loss of function. The experience of becoming a patient, therefore, inevitably commences in the acute paradigm grounded in curative notions and submissive compliance.

Roach Anleu highlights the significance of the changing focus of health professionals towards patients labelled as chronic. Their role has now moved from diagnosis and treatment to social control, to limit the patient’s incapacity - to motivate the patient to be rehabilitated and normalise their life. The aim has moved from curative notions to retraining the patient to effectively perform the roles and tasks to which they were socialised before illness (Roach Anleu, 1991, p.109). As this study evidenced, patients with an injury or functional loss (for example, caused by a stroke, multiple sclerosis, or injury) were acute until their condition stabilised (where no further cure is taking place). Patients are handed back their bodies and their conditions, with the expectation they will regain control of their life, undertaking normalisation programs to limit the impact of their condition that becomes their new goal (as opposed to being cured). When patients are in their home the arrival of the district nurses confers legitimacy due to the relationship between nursing and the medical paradigm.

**Being nursed in the home**

As previously explored, most patients were grateful to be able to receive nursing in the home. It enabled them to regain (or hold on to) their sense of self and to normalise their personal life patterns and relationships. It avoids, or is respite from, institutional health care where the patient is constructed by medical culture, and concurrently, the need to meet institutional needs. In all but two instances in this
study, patients had become district nursing patients, specifically due to the time frame of their condition. That is, they were ageing or suffered from a chronic or malignant condition. It is therefore easy to appreciate the gratitude of patients when they are referred to district nursing.

On admission, prior beliefs, the medical diagnosis (or non-diagnosis) are combined with the nursing diagnosis and the person is converted to nursing language. People became patients by virtue of nursing needs, which are known as self-care deficits. Utilising the language, terms and essence of nursing diagnosis in Alfaro (1990), a self-care deficit implies a person needs assistance to perform activities of daily living, due to their inability to do for themselves, something they would normally do, if they were able (Orem, 1985). Needs are then sanctioned as legitimate by the nursing profession and referred to as normative needs (Bradshaw, 1972). A person’s needs must be legitimate self-care deficits related to health and health maintenance, thereby entitling the patient to society’s health care resources, such as nursing.

The person is now a patient and the district nursing service is the patient’s service provider, attending to self-care deficits that are normative health care needs. In turn, the nursing service now categorises and labels patients according to their diagnosis, prognosis, and the nature of their self-care deficits. Subsequently, in this insidious manner, the very experience of needing nursing subjects patients to judgements, categorisation, labelling and ongoing construction and legitimisation by nursing culture, the annexing hospital, and the local community.

**Being constructed by language**

Self-care deficits and loss of function are an individual’s response to illness and yet the experience is constructed by broader notions of culture. Illness is a deviation from the normal state of health. People are measured against socially constructed norms and the degree of illness is the deviation from the norm that is evident to the outsider and/or legitimised by the health care system. The individual’s experience is then subject to how our culture accepts and allows for the deviation, but also, as will be illustrated shortly, the social construction.

The language of nursing refers to health, disease, illness, and self-care deficits. This language is maintained in medical institutions, such as the service’s annexing hospital, and reflects nursing’s relationship to the medical paradigm. The medical paradigm is, however, contrary to the expression of needs of the patients. That is not to say they do not value and need doctors, rather, that the issue of nursing is distinct from the aspects of care they sought from their doctor.
Patients rarely perceive themselves as being ill, having self-care deficits, or being rehabilitated. They may have a bad day, but due to the chronicity of most patients’ conditions, this means that they need the nurses to come, to assist, to do for or with them, to assess, or as support, to perform tasks, as a means of getting on with life. They use terms such as well, tired or unwell, needing a hand and basic nursing care, to convey complex needs and nursing interactions. Most sought to maintain a subjective state of wellbeing and quality of life in spite of compromised medical status. A state of wellbeing is not comparable with other patients or even the same patient at a different point in time - it is only significant in the context of a patient’s own life and how they feel and manage, from one day and the next. Likewise, as it was noted in *The Nursing Narrative*, when patients were asked about the value of nursing interactions, they did not speak about cure, but quite a different value; they spoke about the nurse coming early, regularly, knowing she would come so they had peace of mind, so treatments were given or needs met and they could get on with their day.

**Being constructed by needs**

The *Patients’ Voices* revealed a willingness, or at least a preparedness to submissively compromise their needs to fit with the nurse’s ways and routines. These patients had been moved from the acute medical paradigm and, as is the consequence of permanency, they appreciated the notion of self reliance that had been returned to them as their new label enabled them to be nursed from home. Nursing is, however, directly related to the medical paradigm, consequently eliciting passive compliance. The rationale for submissiveness, paternalism and an acceptance of benevolence is a belief that the nurse knows best, and to fit with the norm. Patients explained they know who they need now and in the future to maintain their lifestyle and it has become a basic necessity of their life to compromise and modify needs to maintain acceptability. Patients don’t speak out when they are chronic or disabled as the risk is to be labelled with negative connotations or even to receive decreasing amounts of care. That is not always the case, but it is the risk.

As a result patients are vulnerable; categorised and labelled by others who make judgements about their subjective reality. It is not merely a reputed risk but, as Bron’s narrative reminds us, it is very real. In recalling Bron’s narrative, a nurse had used her professional dominance and ignored Bron’s request. The consequence of ignoring Bron as a person was an appalling indignity, whilst the consequence of ignoring Bron’s personal knowledge resulted in a belittling incident that should never
have occurred. Additionally, this incident had profound and lasting implications for Bron and all the nurses, as the experience shaped her interaction with the nurse concerned and any new nurses. I remain at a loss as to why domination was part of the nursing interaction, other than the nurse’s arrogance in controlling and shaping the interaction, resulting in an abuse of professional power grounded in the nurse-patient power differential.

**Patient's experiences of labelling and redefinition**

Returning to the fieldwork, reflective fieldnotes and patient interviews now enables patients’ stories to convey their experiences of the meaning of illness, non-diagnosis, diagnosis and subsequently how this impacted on their lives and their illness experience.

Elsie reflected, with resigned frustration, about the years before she was diagnosed with multiple sclerosis. It was not that an earlier diagnosis would have made a difference to her physical condition, but she knows, now, that knowing and having a diagnosis alters the personal experience of illness. When Elsie began to feel unwell and experienced progressive functional loss, her body was intensively investigated with referrals to an ongoing variety of specialists. Each considered one system of the body as a separate entity, but there were no positive pathological tests, only functional losses and the subjective experience. As her condition continued to deteriorate she was eventually diagnosed, “... on the collection of symptoms and the progression of these symptoms,” by her general practitioner. When Elsie received a medical diagnosis her experience became legitimate, even worthy of re-investigation. In addition she became entitled to many services, to which there was no entitlement without an official medical diagnosis.

Ten years later, Carol has not been officially diagnosed. Her body barely functions and as the loss of function became obvious she was accordingly conferred a degree of legitimacy by her doctors and friends. Carol has made a conscious choice: she doesn’t want to accept any labels, explaining that the degenerative process has already dehumanised her very being. She stays in her home as she doesn’t wish to be seen.

Many of the patients in the home who had chronic degenerative conditions told similar stories to Elsie - only a few, like Carol, had chosen not to partake in the system. For most, diagnosis was a relief, conferring legitimacy after years of being a suspected deviant who sought to escape their normal social role. As Fassett explains,
illness with no known cause has come to be collectively described as psychosomatic states (Fassett & Gallagher, 1998). The paradox of patient centred care is embedded in the disturbing consequences of non-conformity within the health care system. Lorber found the consequences of being labelled a problem patient were “... premature discharge, neglect and referral to a psychiatrist” (1975, p.213). As an insider I also question the logic of feeling ill, being undiagnosed, a suspected deviant and yet expected to get on with life. Those patients in the study in this predicament, frequently explained this was physically impossible, but beyond that, it was all so belittling, a feeling I felt was clearly articulated in Carol’s story. She still seeks medical and nursing support as a necessity to live, whilst as a consequence of the belittling process, she no-longer seeks a ‘label of legitimacy’.

Patients who are lucid know (or soon learn) what needs are legitimate. These patients, in this study, have an overriding desire to remain at home and they want and need a comfortable interpersonal relationship with the nurses. As a consequence, they inevitably do their utmost to remain within acceptable confines and to be perceived as good patients. Cultural norms keep all the participants confined to their roles.

**The cultural norm**

The experience of becoming a patient in this study had begun with entry through the medical paradigm, such as hospitals and general practitioners. The person experiences being converted to a patient followed by passive submission, as is the norm in the acute paradigm. They are actively treated in the acute paradigm but if they fail to meet the cultural norms of returning to wellness within a prescribed (but unknown) time frame, they are redefined. In this study, they had then been referred to the district nursing service where they were to experience a new set of norms of accepted behaviour.

As most patients in the study actively chose to be at home, it was their ultimate objective to have their nursing needs met in the home environment and they soon learnt the norms of behaviour, such as compromising their needs, and being a compliant, cheerful patient. Meeting the norms of nursing culture determined their position as a patient, and therefore what needs would be accepted as legitimate and the comfort of their relationship with the nurses. Patients learnt that it was important, in fact essential, to understand the nurse’s ways and to accept these with apparent pleasure. They only spoke out when their physical integrity was at risk. Therefore, it is a given norm that patients will learn the cultural norms and passively comply.
In addition, it is timely to look again at the flipside, recalling why nurses reinforce medical culture as opposed to their own theoretical underpinnings of the nursing profession. It has been shown that the norms of nursing are a direct consequence of the relationship between nursing and the medical paradigm. Medical culture has determined that nursing is about meeting normative health care needs as determined by the medical profession and, in effect, by society. In turn, normative needs become legitimate needs - by legitimising what are accepted nursing needs medical culture shapes nursing practice. In this way, whilst district nursing occurs in a unique environment where the existing power structures are absent, the cultural norms of practice are shaped as an extension of nursing in institutional environments, thus focusing on tasks, such as technical procedures and clean bodies (Wolf, 1986, 1988). The cultural norm for patients is therefore set within broader notions of society’s cultural norms, and society’s acceptance of the biomedical model of health which, in effect, then ignores the needs of chronic and disabled patients; hence the notions of rehabilitation and normalisation.

By returning to patient’s needs as cited earlier in this chapter, these were inclusive of independence, keeping well, remaining in their home, being with families, and outings with friends. Whilst these are not direct nursing needs, to achieve these outcomes, to be able to get on with their life, it is essential to have their nursing needs met. Health needs are broad and encompassing and need to consider issues of technical procedures and hygiene as well as how (and if) a patient manages; such as ensuring they are up and about and have remembered to eat and take their medication. Without coming from this encompassing, life perspective, that was unspoken between the nurse and the patient, and illegitimate by society’s standards, the nurse misses an appreciation of the patient’s subjective reality and, as Taylor (1994) notes, they miss the opportunity to be therapeutic through the use of self.

**Patient and Professional Ambiguities**

Caldock (1994), Illich (1976, 1977) and Jourard (1971) all question the power differential inherent in the nurse-patient relationship. Power is embedded within the nursing process as nurses set the norms, determine the nursing diagnosis and the patient’s needs. In this manner, the cultural construction of nursing and the power differential between the nurse and patient, insidiously exposes the issues of compliance. Similarly, this notion of dominance is further reinforced by Caldock’s concern about the role of the nurse and their position of power, as they work from a tradition where they have been perceived as having the right of defining both needs and appropriate responses (1994, p.136).
Helle Samuelson (1991) adds another perspective to notions of the power differential as she points out the fundamentally different perspectives of healer and patient. This difference is akin to the insider-outsider notion introduced in Chapter Four. The language of nursing is about meeting patient’s needs by attending to the patient’s story of their illness, but this basic position fails to acknowledge that, for many reasons related to risking themselves, patient’s carefully consider and weigh up the consequences of what they feel they are able to reveal; or that as nurses tend to be outsiders to the experience, rarely are they able to impute the same meaning to an experience. As a consequence, a patient may never reveal the depth of their illness experience and if they do, the meaning they seek to convey may not be appreciated. The experience of being a patient is to be subjected to the difficulties in living that result from sickness (Eisenberg & Klienman 1980; Klienman, Eisenberg & Good, 1978) and yet, as the research has illustrated, patients rarely express needs (such as their difficulties experienced in living as the result of sickness) beyond what they learnt were culturally acceptable.

The previous chapter, Patients and Health Culture: Time and Space illustrated the role of the nurse in leading patients through the various phases of medical culture, from acute to chronic, to rehabilitation and normalisation. Each phase has its own cultural expectations of the patient. Nurses do not question these, rather, they too accept them, encouraging patients through these phases, thus insidiously reinforcing normative culture. In addition, this chapter has illustrated that the medical paradigm dictates the cultural norms which nurses then carry through to nursing practice. The ambiguity of this occurrence is entrenched in nursing’s theoretical philosophical base, which is underpinned by humanism, the basic tenet of which is holistic patient care; patient participation in a collaborative process wherein the patient is central to nursing (Jewell, 1994). Whilst nurses espouse humanistic underpinnings nurses are employed and funded to perform legitimate functions that are sanctioned by society, therefore nursing practice is framed by normative culture. The overall consequence is that nursing reinforces normative culture and, in so doing, dehumanises the subjective experience of being a patient. In seeking to further understand society’s cultural norms, this section now looks at the social construction of a patient by normative culture.

**Holistic care and patients’ experiences**

In beginning to look at the social construction of illness, this discussion seeks to make clear the theoretical underpinnings of nursing practice so that the inquiry can then examine the espoused theory with the experiences uncovered so far.
Nursing theorists such as Benner (1985) focus on holism (also referred to as wholism) as an integral tenet of nursing practice. To nurse holistically implies attending to the patient’s story of the illness and broadens the concept of nursing from a narrow image of specific tasks. According to Kramer (1990, p.246), ‘holism’ is derived from ‘holos’ which has a root meaning of complete, entire, total care, thus the tenets of holism are the connectedness of wholes and parts. Holism cannot be understood by the addition of isolated parts as it is the connectedness and the interrelationship that coexist to give an holistic perspective (Kramer, 1990).

Likewise, Benner and Wrubel (1989) note the language of holistic nursing infers looking at the patient as a sum total of all the parts, as a unified whole, including the mind and body in synchronicity, and as synergistic.

Ong (1991) points out that holism accepts the uniqueness of individuals, and therefore accepts that patients have a right to reveal only what they choose to reveal, and that nurses do not have a right to access another’s ‘whole self’. Ethnographic research by Ong identifies a taxonomy of patients with three distinct ways in which individual patients wanted to be seen by district nurses.

* The first group insisted their integrity as a person was unaffected by their condition. These patients describe physical nursing needs as tasks, emphasising their need to live as normal a life as possible. The role of the district nurses was as a back up. They clearly delineated which tasks were for the nurse and which ones for themselves and others.

* The second group regarded their disease or condition as a discrete episode in their life and attempted to limit its impact. As with the first group, they delineated clear territories for the nurses, describing needs as tasks. For example, whilst the nurse may come to dress a leg ulcer, the frail unstable patient will accept assistance offered (such as with showering, hygiene and medications).

* The third group saw their condition as a total impact on their life. They considered their illness as pervading their way of being and expected the district nurses to deal with the totality of needs.

Ong also found that the way a patient wanted to be seen was dependent on their sense of self. Sense of self was found to be related to their forced change of lifestyles and values as a result of their illness, such as the impact on personal goals, significant others, privacy, and finances, rather than the severity of the disease (Ong, 1991).

Benner and Wrubel (1989) also describe nursing as being about responding to the practical difficulties experienced in living as a consequence of disease and its
treatment, focusing on attending to the patient’s story of the illness. With some similarity, the mission statement of the district nursing service in this study cites nursing as

... a dynamic process aimed at enabling individuals to remain in their own homes by improving, restoring and enhancing, or maintaining the client’s levels of independence and quality of life (district nursing service leaflet).

When a patient chooses to be seen in a specific way, this is not a negation of holistic care, rather, an opportunity for real holistic care, in the sense of not overriding a patient’s values. The imperative aspect is to choose to respect the patient’s expressed needs and to know that what they say is by choice, not the consequence of a power equation.

**Who defines needs?**

It remains problematic that, whilst the nursing profession espouses holistic care, in reality the framework of nursing practice is grounded in meeting normative health care needs. Society, normative needs and the allocation of resources through the funding hierarchy, shape the role of the district nurse by constructing what legitimate health care needs are provided and accessible, in a given community at a given point in time. As normative needs are ultimately given shape by dominant socio-political structures, regardless of how different they are from nursing values, or most importantly, from patients’ values, the notion of normative needs and patient centred practice are opposing ideologies. However, as the study focuses on the nurse-patient relationship, it is therefore necessary to focus on the nurse’s role in defining needs as their assessments determine a patient’s accessibility to given resources.

As previously noted, the assessment of needs is grounded in nursing culture, socialisation and enculturation. Nursing assessment remains a contentious issue because the concept of needs is normative, that is those laid down by the profession, and additionally, what needs are accepted as normative for a given patient are strongly influenced by value judgements. The judgement of needs, and the subsequent nursing allocation, continued as an issue that varied even between different nurses on different days. Some patients expressed needs beyond normative needs and, in reality, there was no clear delineation of what needs were, or were not acceptable, although they tended to be those associated with the public imagery of nursing; aiding people with hygiene and bodily needs and technical procedures related to bodies and health. What the nurses accepted as needs were found to be underpinned by their relationship with that patient in the community (for example a
close friend or relative where the nurse wanted to be, or wanted to be seen to be, special) and, specifically, by the underpinning ideology from which they practised.

Whilst nurses, per se, reinforced normative culture, many nurses practised with humanistic characteristics in a personal, caring relationship with patients. Particular nurses crossed the cultural barrier of what society and their funding body accepted as legitimate nursing tasks, regardless of time constraints or institutional directives. It was, however, a practice necessitating personal sacrifice, the use of creativity and even subversion, as felt needs or wants (Bradshaw, 1972) are not legitimate nursing needs. These nurses integrated and maintained the underpinning ideologies of professional nursing practice with humanistic nursing, giving of themselves to enhance the integrity of patients as unique individuals, covertly accepting their living reality. These nurses accepted the need to draw on their personal time (as in general, these nurse-patient relationships were reciprocal), whilst society then accepts the nursing action as legitimate simply because the needs were met in personal time.

In returning to the emic (subjective) experience, issues of power embedded in the social and cultural construction of the role of nurses in the health care system, alongside patient needs and social justice issues, paint a rather disconcerting picture of holistic philosophy. Funding reflected government health care policy, then institutional goals, whilst the scarcity of nursing resources, constructed an overriding reality gilded in jargon such as ‘empowerment’. What does this infer? It infers that nurses reinforced society’s cultural values and elicited a reciprocal response from the patient - the patient was grateful to the nurses (who gave so much) and so they try for their sake and embedded personal gratitude swayed attitudes. The patient meets the cultural norm, working towards policy-dictated outcomes, not their own goals.

At this time in history (1994-1999), social justice notions challenge the status quo, as the dominant social voice of health care policies is driven from an economic power base of financial profitability. Health care policies are not the consequence of a society that cares for people simply because they are human and their needs matter. Despite this, as the study has noted, some nurses act subversively and covertly to meet patients’ needs. These nurses reveal a tempering of power and social construction. Power is tempered by the very nature of many nurses who choose to work in district nursing, and by their reciprocal relationship with patients as interdependant members of a rural community.
Social construction

At the local level of nursing services, it is nurses who determined the legitimacy of needs and who gets what. Variables such as power and needs were negotiated to a balance that never remained static. Ways of nursing, the philosophical underpinnings of practice and patient issues, such as how they wish to be seen, have been highlighted. This section now turns to the social construction of being a patient and the legitimacy of needs emphasised in the literature by Leeder (1992), Littlewood (1987), Lorber (1975), Lupton (1994), Jeffrey (1979), Holmes and Warelow (1997).

Allocation of needs at the most basic level of daily practice was dependent on interrelated forms of evaluation, taking into account the cover terms of social status, history within the community, causal relationship of the illness or condition, and distance; all of which are innately part of socio-political issues such as the allocation of scarce resources and culturally legitimated needs. No factor stood alone and whilst each cover term is explored independently, the culture of nursing and the experience of being a patient showed how these concepts are interwoven to influence the amount of care and attitude to a patient in varying degrees.

Social history

In rurality, a person’s social history in the community is inevitably a known factor. Social history, as a cover term, includes aspects of occupation, income, personality, appearance, age, attitude and acceptable behaviour within the context of the community; secondly, within the context of the nurse’s social community; whilst thirdly, it included the patient’s response to illness and whether this is within the culturally acceptable norms.

Causal relationships

Causal relationship is the cover term that relates an illness to the assumed cause of the disease (described in the literature by Jeffrey, 1979). The general thrust of causality is that if a patient has caused their condition (for example, due to smoking, alcohol, non-compliance with medical advice, or an accident that the community deems negligent) then this patient is seen as less deserving. In this way causality highlights the social construction of illness which is at odds with notions of holistic care and equality.
The legitimacy of illness forms a continuum, dependent on the nature of a particular community and the personalities and values of the people who are making judgements about others. It is also only one aspect amongst a group of variables and can never be perceived as impacting alone.

The causal continuum begins with high profile illnesses that accommodate curative expectations, such as acute illnesses. For example, blocked coronary arteries are not considered in relation to the potential cause and are regarded as important to treat, cure and care for. Alongside this are sport injuries that have a direct causal relationship, but one that is negated when the injury is caused through participation in high profile social activities such as football. The continuum spirals downwards through chronic debilitating illnesses that are not embodied in technological or curative expectations. These are ‘unfortunate and beyond the patient’s control’ but they will need to ‘learn to live with it’. Included in this category are conditions such as multiple sclerosis, asthma, dementia, chronic coronary artery disease; and permanent impairments such as quadriplegia or brain injuries as the consequence of accidents, regardless of the circumstances. At the lower end of the causal continuum are illnesses that are assumed to be self-induced and have limited curative expectations such as emphysema. The inference being that ‘you have caused your illness’.

Health professionals make generalisations about the illness experience and needs of those with chronic conditions. A cerebral haemorrhage may be significant when it occurs (as in needing acute intervention and medical support) but eventually, due to their permanent loss of function, these patients are reclassified as chronic, for basic nursing care. These patients become a silenced entity (such as back pain) alongside invisible, incurable, frustrating conditions that rarely respond positively to treatment because of the aetiology of the condition. Chronic loss of function such as impairments and acquired disabilities are areas where it is expected that the patient and family need to learn to cope and to modify their needs to a greater extent than acute patients. Community status and the nurse-patient relationship are positive factors that aid in balancing out these discrepancies.

**Distance**

The World Health Organisation, health policies and hospital rhetoric all assert that health care should serve and meet the needs of populations, therefore the notion of distance, a socially constructed variable, provides further insight into the vicariousness of being a patient. In this community, distance was the harshest
variance. It was irrelevant if the patient lived in the town but, for those who resided in the shire run, there were discrepancies in access directly related to distance. When a person lived further from base, the time and mileage and therefore the cost of meeting the same needs, increases accordingly. When equal funding is allocated to patients with comparative needs, this infers that rural and more remote patients receive less actual time for the provision of nursing and, it is a decision which is made at the local level. As a result, accessibility to home nursing was profoundly complicated by distance resulting in comparative inequities of nursing time per visit and the frequency of visits.

Australian research has already demonstrated the inequities faced by people who live in rural areas and need district nursing (Crebbin, 1994; Melko, 1992). Caldock, (1994) reinforces lack of access (and hence equity) as rural areas may be excluded because of low population and high mileage costs. Bureaucrats use language such as equity, fairness, and justice alongside effectiveness, efficiency, and cost effectiveness in an ambiguous manner that ultimately discriminates and is unjust to people who live in sparsely populated rural areas (Barribal & Mackenzie, 1993; Naish & Kline, 1990).

**Culturally legitimated needs**

The cultural legitimacy of needs acknowledges all the above factors as variables, but seeks to understand the influence of local culture. This was done by layering expressed needs with normative needs over local culture. The study illustrated that when patients in the same area were assessed as having similar normative needs and expressed needs, this was not consistently reflected in nursing allocations. This inconsistency was visible to people in the community and to patients in the study.

Earlier in this thesis, the single, isolated patient who was home alone, with no one to advocate for them, became visible, but as time went by, I was to learn that many patients who were isolated in their homes due to illness and disability had an interesting knowledge of the community. Patients talked about their friends, family and others in the community who were patients of the service. They compared the circumstances, the frequency of the nurses’ visits and what the nurses did at different homes. They could also compare different nurses in similar circumstances. Some made comparative judgements about entitlements to nursing, whilst others just knew because they talked on the telephone to their friends about such issues. Being nursed and the allocation of resources was a major part of their lives and therefore was a major topic of conversation with friends. When patients were aware of discrepancies
they never considered addressing these issues with the nurses as this could put them at risk of being perceived negatively.

From a nursing perspective I was left wondering how a patient internalises the sense that they received less nursing support than someone else in a comparative situation. My response is to go back to the inquiry which has demonstrated that a patient’s allocation is a combination of factors. Only some needs will be normative needs (as those laid down by the profession), compounded by distance, causal relationship of the condition, and their social status and history within the community; together these construct what is culturally legitimate, at a given point in time for a particular patient.

 Allocation of scarce resources

The allocation of nursing time also remained an issue of constant disparity. The nurse and patient negotiate and prioritise needs and the nurses then make decisions and inform the patient. In this way, power was imposed on nurses by a system that employed them to nurse at the coal face of clinical practice; that meant making decisions to allocate scarce resources - that is, who gets what care. In a negative sense, nurses enforce political ideology and social conformity, whilst from a positive aspect, the nurse has the opportunity to make professional judgements based on nursing knowledge, community knowledge, and patient’s circumstances.

Amid the pros and cons, this structure placed nurses in a predicament, bound by the mission statement that espoused holistic care and implied equity, yet being accountable for the allocation of scarce resources which result from socio-political decisions. Nurses are also the public face of the health care system, which means they bear all the public opinion and imagery inclusive of caring outcomes, the tensions from lack of resources and hence lack of care, and even public accountability for patients or people who refuse home nursing and who are later found in appalling health and or hygienic circumstances.

 Cultural Complexity

Cultural complexity acknowledges that even the simplest interaction is imbued with a multitude of cultural meanings. Nursing is a cultural interaction implying common patterns that shape behaviour. These patterns and the power of culture need to be drawn out and appreciated if one is to understand the shaping of cultural norms and how and why these then give meaning to people’s experiences. Culture is powerful
because of its taken-for-grantedness; because it is shared; and because it is communal. The power of culture is then affirmed by the ability of the group to influence personal experience (Peacock, 1986, p.40).

The dominant cultural issues found were, firstly, the construction of normative culture that nurses carry out in an insidious relationship with the medical paradigm; secondly, the social construction of the experience of being a patient and being nursed; and thirdly, the ongoing gratitude of patients which, in turn, enables medical culture to have power over the patient’s experience. As a consequence of these issues, but more so because patients are vulnerable and grateful, they are silent, they only say good things, and so the whole health care system is shaped and given meaning by the biomedical model of health, despite the fact that this model and the notion of normative needs conflicts with the experience of people who are patients and with nursing philosophy. As the thesis consistently reveals, the power of culture, of the need to be obliging, to fit in and be a good patient, means that nursing is grounded in social and cultural norms rather than functional needs. The nursing assessment and the subsequent allocation of nursing resources occurs on a conscious and sub-consciousness level. Similarly, patients and nurses can see variations in the amount and forms of assistance, but rarely can this be explained. They just are.

In spite of the social construction of being a patient, nursing has a counter role which, in effect, sanctions the intimacy and complexity of nursing private bodies in public communities. In the first instance, the patient’s deviation from normality is legitimised by images of nurses in uniform arriving at a home marking the person as a patient. Secondly, employing the term basic nursing care avoids the verbalisation of private, intimate interactions on bodies, enabling much of nursing practice to remain in the patient’s private world. Patients are able to maintain a sense of cultural normality when personal procedures are subsumed in professional language, are performed in the patient’s private domain and nursing images legitimate the deviation from wellness.

**Summary**

The concept of being a patient was found to have evolved over time, alongside the mode of production of medical knowledge. This overview of changing medical cosmology enabled an appreciation of how the medical profession became so dominant in our current day health culture. It also provides insight into the way doctors, nurses and patients are expected to behave and why submissive compliance is the cultural norm. From this understanding, I then looked again at the experience
of becoming a patient and the cultural norms a patient is subject to throughout the various stages of the illness experience. An understanding of being a patient is fundamental to the thesis, yet it became increasingly clear just how complex the social construction of nursing was and, that this complexity needs to be understood.

Further discussion highlighted the ambiguity of the term ‘needs’ where the social construction of a patient and normative culture determines legitimate nursing needs. In fact, it has little to do with the patient’s perception of their needs or notions of collaboration with health care providers such as nurses. Political, institutional, community, and cultural dynamics are vicariously balanced (by outsiders) to determine legitimate needs for the person who had become a patient. As these factors are unique to individual patients, so is the precise nature of legitimate needs in any given instance. It is questionable, then, whether nursing’s professional ideology about the importance of patient-nurse relations and patient-centred-nursing is practiced in day to day situations.

The discussion has revealed that, in reality, there is a discrepancy between the professional role of nurses and their espoused philosophical underpinnings and the experience of patients. It is argued that nurses do not practise within a patient’s frame of reference, rather, they work within a cultural frame of reference which is transferred benevolently to patients as being in their best interests. It is the cultural norm that is reinforced by the medical paradigm and employing institutions, yet it conflicts with nursing philosophy; namely humanism, patient participation and the centrality of the patients’ values to nursing practice. In summary, nurses allow cultural norms to override nursing philosophy and theory. As a consequence, nurses and nursing practice is very powerful as they are instrumental in reinforcing social norms which, in turn, give meaning to the experience of illness and shape patients’ lives.
This final chapter now returns to the introduction to summarise why this inquiry was initiated, what it set out to achieve, and what the inquiry found. The chapter will then reflect on the findings and their implications for nursing practice.

The overall objective of the research was to understand why it is the cultural norm for patients to experience submissive expectations. Subsequently, the inquiry sought an anthropological perspective and an insider’s point of view about the culture of nursing to uncover the common patterns of behaviour and roles of nurses and patients, with a specific focus on how culture gives meaning to, and thus shapes, the experience of being a patient.

The study found that nursing is profoundly influenced and shaped by the norms of health culture prior to the nursing interaction and that consequently, it is not realistic to consider nursing as an isolated culture or phenomenon. The conclusion therefore looks at nursing and being nursed within the context of health care to provide insight into the layers of health culture. Firstly, the findings draw out the insider-outsider contradictions of health culture. The dominant view, the cultural norm, is the outsider’s view, whilst the insider’s perspective is that of the participants who spend an extended length of time within this culture. Secondly, the findings expand on why this has occurred, by looking at the roles and inter-relationships of those who participate in this culture. Thirdly, as the movement through the stages of health culture are discussed, a map or pathway and the associated rules through health culture become self-evident. The pathway illustrates the norms of the health care system, that give meaning to and shape the practice of nursing and in turn, the experience of patients. The conclusion then re-examines the role of nursing in reinforcing cultural norms and the subsequent implications for patients, contrasting the reality of what occurs, with nursing theory, respect for persons and the implications of cultural understanding for the profession of nursing.
The Findings

This anthropological study, using the ethnographic process, looked at Western health culture in rural Australia to describe the nurse-patient interaction and the cultural norms which shape and give meaning to patients’ experiences. The health care system exerts an important influence in our culture. Whilst the inquiry confirms that health professionals are perceived by society as having the knowledge to treat symptoms and to care for our physical and emotional wellbeing, to return the sick person to wellness, I was to find that this was not the experience of those people who became patients yet who unwittingly failed to be cured. *The Nursing Narrative, Patients’ Voices, Patients and Culture: Time and Space, and The Cultural Norms Shaping Patients’ Experiences*, each form levels of understanding; they build on each other, adding a variety of perspectives and meanings to what originally appeared as isolated incidents or patient experiences. In the end, they reveal a complex culture with many participants, various roles, norms of expected behaviour and associated sanctions for those who do not meet the norms.

The study focused on nurses and patients in the context of nursing in the health care system, as a group of people united by common concerns. In the process of living and working together, norms of acceptable behaviour are formed, representative of dominant ways of thinking that are implicit and implied, shaping and constructing the interactions of participants. It is the norms of the health care system, that give meaning to and shape the practice of nursing and in turn, the experience of patients. It is coming to know and reveal these beliefs, attitudes and behaviours, and how they construct interactions, that is the final purpose of this research.

The study found that the norms of health culture fail to appreciate the reality of being a patient from the insider’s perspective. Health culture is an outsider’s perspective.

- Outsider images regard patients as passive recipients, failing to acknowledge personal beliefs and needs of patients that may not coincide with the benevolence of the health system.

- Outsider notions of cure do not appreciate the dilemmas of patients who fail to meet normative expectations. The cultural norm equates with the medical paradigm, with submissive compliance, cure and prescribed time frames, thus ignoring genetic, iatrogenic, chronic, degenerative, and malignant illnesses and injuries.
• The outsider perspective of health culture fails to acknowledge the living reality of participants: the experience of illness; the process of being powerless; the process of returning to health; or where a person lives with an illness and life goes on. This view therefore fails to legitimise the multiplicity of experiences of people along the continuum from illness to wellness. In fact, it fails to appreciate the coexistence of illness and wellness.

This dominant outsiders’ image of health care culture initially appeared quite logical, yet it is a simplistic even glorified explanation that rarely correlates with peoples’ (patients’) experiences. It is a scientific fact that not all illnesses are curable, thus it is inevitable that many people fail to meet these cultural norms and will continue to endure the subjective experience of illness. These norms allude to a loss of humanity within our culture, as people who become patients, yet fail to respond to curative notions, are moved through stages of health culture. Each stage has its norms or expected patterns of behaviour and consequences of non-compliance, yet these norms were rarely within a patient’s control. As a consequence, the ethnography revealed patients struggling to be accepted.

The conclusion, therefore, provides a picture or map through the complex cultural expectations which are normative behaviour for the person who becomes a patient. The map seeks to make known the implicit meanings, norms of behaviour and unwritten rules that a patient needs to understand as they pass through various stages of the health care system and health culture. The fundamental significance of these norms is illustrated in the consequences of not understanding the nuances of this culture: those who speak out, who question expert knowledge, are not grateful or who do not accept the status quo are deviants within their own culture. As a consequence they are in danger of being perceived and regarded, by those who purport to care for them, as nuisances or malingerers. That puts them at risk of receiving less care, being hurried, treated roughly, or being discharged. But their experience goes beyond this in so far as these patients’ attach meaning to such behaviour. The effect of these attitudes on patients is to make them feel vulnerable, at risk, dehumanised and a lesser person, impacting on their sense of self.

Reflecting on participants’ roles in health culture

The evolution of medical science, the industrial revolution and a patriarchal society have shaped the normative culture of sickness from an integrated relationship between a doctor and patient to the dominance of medical knowledge over patients (Jewson, 1976). As the sick-person became an object, medical science became an
Chapter Ten: Making Sense of Health Culture

elite body of knowledge, unquestioningly exerting assumed power over society. Consequently, the biomedical model, with associated images of cure, became the norm in our society where scientific, medical knowledge now dictates the patterns of normative behaviour.

Another consequence of medicine as the dominant form of knowledge was the lasting implications of the division of labour in health care. Dingwall et al. (1988), Jewson (1976), Palmer and Short (1989) and Samuelson (1991), all agree that the health care system is hierarchically structured according to the power of knowledge. Medical knowledge is the cornerstone of health care, considered as elite and sanctified, followed by nurses lower down the hierarchy with other health professionals who are service providers, and finally, at the bottom of the ladder, are patients, the people who are recipients of health care.

As service providers, nurses carry out historically embedded roles - that of carrying on the observations and procedures in the doctor’s absence (Dingwall et al., 1988) and the nurturing role of caring for the environment, the cleanliness of bodies and comforting and supporting patients (Hagger, 1976; Summers, 1975; Wolf, 1986). More recently, the nurse’s role, to care, has been recognised as therapeutic in its own right (Leininger, 1988; Taylor, 1994; Watson, 1985).

Nurses are, however, in an ambiguous position, as was clearly evident within the ethnographic narratives and is captured in Helle Samuelson’s observations.

On one hand, the nurse’s job is to implement the orders of the doctor; she is an extension of the doctor and what he stands for, on the other hand, because nursing is historically associated with female qualities of caring, it involves understanding and even solidarity with the patient (Samuelson, 1991, p.191).

Doctors construct and are constructed by the dominant medical paradigm, but it is also a reality that nurses work alongside the medical profession. They too are participants in health culture and act according to cultural norms. Nursing is very much a part of the medical paradigm, participating, shaped by, and reinforcing the cultural norms.

The Pathway or Map Through Health Culture

Health culture is dominated by medical concepts of illness and cure that infer health is a singular value referring to the absence of illness - a value that has become society’s norm. As the ethnography has illustrated, this is a simplistic imagery which
fails to represent the reality of people who experience illness. Reality is far more complex. It is unspoken, it is unconscious and it is implicit; yet there are rules that form a pathway or map through health culture, which is now made explicit in the following discussion

**Level one, entering the health care system**

Within our culture, being sick means having a self-care or health deficit that is legitimised through medicalisation. People enter the medical paradigm having deviated from health and, in such circumstances, it is the norm to seek advice. The doctor undertakes tests and, on the basis of objective empirical results the person will either become a patient admitted to the biomedical paradigm, or in effect, their subjective experience (symptoms) may be dismissed.

If they are legitimised and enter the medical paradigm there are norms, that is, common patterns of expected behaviour. These norms include passively accepting benevolent paternalism, being compliant and being cured. It is the norm for the bureaucracy of this system to paternalistically make decisions for the patient. The nurses, for example, ‘negotiate’ care plans which, in effect will direct the patient’s treatment, such as, what will be done *for* and *to* them. Other norms that influence the acceptance of a person as a patient have been illustrated in the social construction of illness, and include having a pleasant, obliging personality and being grateful. In a rural community, the community status and the patients ability to get to health professionals rather than seeking them to travel and thereby utilise resources (time and travel costs), are important considerations.

Entry into the medical paradigm implies a search for scientific explanations and, similarly, ongoing searches for empirical evidence to maintain legitimacy. It is also an assumed norm, that if a patient is compliant they will be cured within prescribed time frames. These time frames are basically unknown, whilst in Australia at the current time, Diagnostic Related Groups is an empirical measurement of the time needed before a patient is moved on. Basically however, our society seeks and values cure and, as compliance equates with cure, it is easy to understand why society accepts this as the norm and why patients are submissively compliant. The power of the cultural norm has another strength, however, as the price of not accepting the norm, of non-compliance, or speaking out, is to be a deviant in one’s own culture. The rationale for patients’ submissive compliance is patently clear.
As previously noted, some patients do return to health. Some may only experience a minor deviation and be legitimised by the profession and manage to continue their life. Some will have their symptoms, their experience negated, others become marginalised and move around the fringe of medicalisation; seeking further tests, assistance to manage, or even answers. They are referred to as difficult patients.

**Level two, being moved on**

The next stage is being moved on. The patient is redefined as chronic, the ‘bed’ is needed for the next patient, time frames associated with diagnostic related groups have been consumed, and/or the patient’s condition is stable (the tests regularly show the same empirical value).

Medical status will always significantly influence and give meaning to a patient’s experience, but for most, at a certain point in time they are expected to move on. Certainly, if a patient remains unwell they are moved to the second cultural level of being a patient. As time goes by (as an abstract notion that is not quantifiable or explicit), when there is no cure, the patient is handed back their unwell body, with self-care deficits and symptoms. Its not a callous process of intent, but it is dispossession by the medical profession who previously validated the person’s illness and sought compliance.

Nor does non-diagnosis provide any answers for a person who is still experiencing symptoms. In fact, it can be very devastating as the person’s subjective reality is denied. The absence of tests to confirm illness implies the person must be well, or that there is another reason for their symptoms, based on the assumption that the person may have had a traumatic life experience, or may benefit socially from being ill. These patients struggle, perhaps experiencing barrages of tests but, if these do not empirically confirm disease, these patients may be designated as ‘a psych consult’.

The pathway after this depends on the outcome of the consultation. It may mean further consultations or they may be returned to the physicians or their symptoms negated.

From here there are two main destinations depending on the pathological tests and the medical opinion. Patients who remain unwell who have not been diagnosed tend to be referred on for a psychological explanations of illness. However, if no causal explanation is found by the psychiatrist, the patient re-enters the next phase - they move to rehabilitation and/or normalisation. Conversely, patients who have been
diagnosed but not cured are accepted as having a legitimate illness. In not meeting normative time frames for cure, the cultural norms decree these patients must be moved on. Similarly, they are referred to rehabilitation and normalisation programs to limit the impact of illness and disability.

**Level two (a) - ‘a psych consult’**

MR’s narration (in Fassett & Gallagher, 1998) encompasses the essence of many participant’s stories when no pathological disease process could be found to accommodate the illness experience. MR’s is not a unique story, but one that became all too familiar throughout the research. The experience of becoming ‘a psych consult’ impacts on patient’s sense of self as it infers illegitimacy, whilst the change towards MR by the nursing staff was yet another inference of loss of worth.

[MR explained] The nurse stopped caring for me from the time a doctor wrote in my history *For a psych consult*. The whole manner of the nurses towards me changed yet none of them ever discussed the issue with me. I was left for long periods of time and was frightened and lonely (Fassett & Gallagher, 1998, p.95-96).

Fassett notes that when the doctors couldn’t explain MR’s subjective experience of illness through pathologising MR’s body, the alternative was to try to explain MR’s illness through her mind.

**Level two (b) - for rehabilitation and normalisation**

Some people were eventually given a medical diagnosis, but it may have taken years of ongoing negation of symptoms before a diagnosis was confirmed and, therefore, it had no meaning as the patient was initially moved through health culture. For example, recall Bee’s story about Lupus, from chapter eight, where Bee described the frustrations and indignities she was subject to by health professionals, such as being labelled neurotic, for many years before diagnosis.

At this point in time, those with chronic illnesses, degenerative conditions and functional deficits as a consequence of injury or illness must move on. It is now the expected norm that these patients will act to limit the impact of their illness through retraining, such as rehabilitation, physiotherapy and normalisation. The patient is referred to nurses who now frequently become the main health professional. Nursing theory suggests that nursing seeks to understand the patient’s experience yet, in reality, most nurses adhered to routines and rituals, providing tasks for patients.
District nurses now go into the home to carry out the doctor’s orders and meet patients’ self-care deficits, whilst helping the patient to learn to adjust and perform activities themselves. What needs will be met is a ‘negotiated process’ dependant on the patient’s social construction (as discussed in chapter nine), what needs are accepted as normative by the nursing profession, and to fit within the nurses preexisting workload. Assessment and allocation is conscious and sub-consciousness, and whilst patients and nurses could see variations in the amount and forms of assistance, rarely were these explainable.

Flipsiding the notion of rehabilitation that is seen in such a positive manner in our community, requires re-visiting patients’ experiences. An example of this is drawn from the fieldwork by recalling Vera’s situation, who at eighty-three was recently discharged from hospital with ‘residual’ left hemiplegia and now lived alone. A nurse explained an outline of the nursing plan - Vera would be allocated as much support as the service could reasonably provide, relative to the patients needs, the nurses existing workload, and available funding. It was also assumed she would attend a rehabilitation program and that over time, the amount of nursing assistance would decrease as Vera adjusted to her situation. On reflection however, the nursing vision focused on returning Vera to her previous role in the community, and the provision of nursing was based on a regime, derived, albeit implicitly, from the expected norms of health culture. It was not nursing centred around the patient’s needs.

Both MR and Vera have profound impairments and any activity, even the mundane functions of daily living, confront these patients with a difficult physical struggle. For both, there was an implicit assumption that they could adapt or be rehabilitated; and this assumption disregarded their diagnosis, functional loss, and gave no consideration to their personal decisions. This is the cultural norm, however, and therefore society’s expectation of the patient’s pathway and of what nurses do to lead patients along this pathway.

Concurrent with notions of rehabilitation is the concept of normalisation. As the patient is being normalised (which implies they are being retrained to perform activities of daily living to limit the social impact of their condition) the doctor moves into the background and nurses come less frequently. Patient’s days are expected to take on a new structure. Retraining continues with appointments (organised by others) at day centres, rehabilitation centres, education sessions, family meetings and prescribed exercise and/or medication regimes.
Level three, getting on with life & the wellness paradigm

Patients in the first group, who were ageing and accepted their loss of function as a natural part of the ageing process, tended to move straight to this level, accepting their loss as normal. They were grateful for any assistance to get by in life, as exemplified, for example, by Jim and Ellen’s stories. Those patients in the second group were very accepting of their predicament but, due to functional losses, managing was a very difficult process and the experience of rehabilitation and retraining programs tended to be negated, as was the reality of potential outcomes; as exemplified in the stories of Vera, Scotty and Sandra. For the patients in the third group, who tended to be young and who were experiencing very limited and significantly altered lives, had usually entered and spent an extended length of time in the acute paradigm, along with curative or retraining expectations. The changes in their lives, their hope in the acute phase, the intense expectations imposed on them to rehabilitate and normalise their lives, shaped their illness experience quite differently, as exemplified by Raewyn and Bron’s stories.

Finally, having moved on from rehabilitation, psychological consultations and ‘figments of imagination’, some people are able to enter a different paradigm where permanency, chronicity and malignancy do not equate with illness. When the patient has finally moved through the health care system, possibilities began to re-emerge (for some patients). The shape of each day is no longer dependant on tests, results, cures, or the opinions of experts.

Wellness is quite distinct from health. Health is merely an objective measurement declaring the absence of disease, confirmed by a string of negative or normal value pathological tests. Wellness, however, is acceptance of the person’s subjective reality. The intrinsic concepts of wellness and wellbeing are “... a good and satisfactory existence as defined by the individual” (Glanze, 1990, p.1246). Wellness, hence, forms a major paradigm within health culture, but it is not the dominant norm. It is subjective and subjectivity remains tainted in our culture, lacking empirical credibility.

Wellness is illustrated through the nursing narratives when the patient and nurse focus on how a patient feels, how they manage their activities of daily living and what the nurses can do to assist the patient to achieve wellbeing, with acceptance of the change in their lifestyle. Illness, symptoms and deficits are only significant as factors to be overcome or worked around, so patients can get on with life. They are only significant to the degree to which they stop the patient from functioning with reasonable ease, as a subjective perception of the patient.
Summarising the pathway

The pathway through health culture began with entry through the biomedical model of health as the consequence of symptoms or injury. The doctor then undertakes tests and, on the basis of these, either diagnoses or dismisses the person. Diagnosis will lead to an ongoing barrage of tests to continue to confirm the illness and the level of illness in empirical terms. The patient may be admitted to hospital where their experience is shaped by the institutional facility, along with the doctors orders to which the patient will be passively compliant, as is the expected norm. It is assumed that if a person is compliant they will be cured within prescribed (yet non-explicit) time frames.

At this point some return to their previous state of health or a state which is only a minor deviation from before illness, so that they are able to function within reason. They might exit the health care system or may need to stay on the fringes, for regular tests to confirm their wellness or conversely, they may require ongoing support.

Others, however, at a given point in time, are moved on. This may be explicit, or it may simply insidiously occur. Sometimes, the way this occurs is so embedded in daily routines and practices which are accepted as the norm, that we do not even realise. It just is. They will become a psych consult and/or for retraining, shrouded in the terms ‘rehabilitation’ and ‘normalisation’. Regardless of their health status, this is the difficult and unknown stage for patients who experience chronic illness or permanent self-care deficits.

The final stage is when (or if), a patient is able to move on and focus on life, in spite of the symptoms and associated health care activities. These are no longer the sole focus of their life. Patients take various time frames to move through various stages and some stop at different places and never move on. Others leap from diagnosis to getting on with life. The pathway however conveys the essential nature and structure of health culture to the patient so they have an insight into the meaning of what is occurring.

What this means for patients

The patients narratives in Patients’ Voices and Patients and Health Culture: Time and Space, illustrate the power of cultural norms in moving patients on. Patients do not recognise they are being moved on, or that this process is not to achieve their goals, it is just how that the biomedical model and therefore our health care system functions. Patients have been expected to conform to scientific regimes, they assumed cure, yet
Chapter Ten: Making Sense of Health Culture: Page 219

the focus of treatment changes. No longer are they allowed to submissively accept medical and nursing regimes and search for scientific explanations. They are handed back their life, expected to relearn to manage their body or illness with minimal assistance. The symptoms are still present, the subjective reality has not changed, but the focus of the treatment has.

Taylor sums up a person’s entry into health culture “... as an accident of geography and calendar” (1972, p.110), inferring that how one is perceived, the direction of treatment and the pathway which a patient will be expected to follow are a sheer coincidence. Whilst most people expect to get ill at some stage in their life, they know it is the norm to seek out the acute medical paradigm. They don’t necessarily know that entry into health culture implies their life is now controlled by others, or rather, that although they have rights, it is the expected norm that they will be compliant with expert advice.

**Nursing Reinforces Cultural Norms**

Having drawn out the broad social construction and society’s norms, the ethnography now re-focuses on nursing interactions, specifically from the perspective of patients. The discourse now centres on the trajectory of the patient’s experience through health culture.

Focusing on the patient nurse interaction simply reinforces the broader concepts of health culture where patients enter the health care system with expectations of cure and conversely, the expectations on the patient of compliance. The norms of health culture say much about nursing, as patients become submissive and compliant and health professionals, inclusive of nurses, expect this. Because these are tacit, taken-for-granted norms that occur at a subconscious level, there is not a clear understanding, by either party, about this construction of reality. Nurses elicit and reinforce compliance and, likewise, patients know this is how they must behave though, as the introduction to the research suggests, the reasons for the expectations and subsequent behaviour are not understood.

There are three specific reasons why it is problematic that nursing seeks and then reinforces compliance.

- This process contradicts nursing knowledge;
- Nurses actively partake in the social construction of patients; and
- Nurses actively partake in moving patients on.
Nursing knowledge

The first is that nurses are health professionals who have a deep knowledge base and a wealth of practical knowledge and they know there is only a limited correlation between compliance and cure. Nurses are well aware of the manner in which patients are frequently treated as objects under study which subjects the patient to a very dehumanising process. They are also cognisant of iatrogenic illnesses, wrong diagnosis and non-diagnosis. In addition, nursing theory and much scholarly literature about nursing practice, suggests patients are central to the nurse-patient interaction and that nurses care about the patient’s illness experience, rather than narrowly focusing on cure.

Whilst nursing is underpinned by theory and philosophy, nurses are also members of the broader society in which they live and interact and, as such, they have learnt the cultural norms. It is the cultural norm to accept dominant medical knowledge and to regard those members of a culture who contradict cultural norms are deviant. The later chapters of the ethnography illustrate nurses eliciting compliance and reinforcing medical and nursing regimes.

Nurses partake in the social construction of patients

Secondly, as the ethnography revealed, a patient’s illness experience is also a social construction and nurses partake in the construction of another’s illness experience. When people enter the health care system their experience is not merely constructed by symptoms, but by a pre-existing hierarchy of knowledge, alongside expected norms and patterns of behaviour that patients need to learn and conform with. Whilst being a patient is a subjective experience, how a patient is seen and treated by society and the health care system is an objectified process and a socially constructed value judgement. The norms of health culture infer any deviation from the norm of health is defined as illness (Alexander, 1982). People are then measured against socially constructed norms and the degree of illness is the deviation from the norm that is legitimised by the health care system and by society at that given point in time for that individual. As the previous chapter has also illustrated, nurses, as part of the community, are also those who make professional and personal value judgements about another’s experience.

Nurses actively partake in moving patients on

The third complexity is the unknown progression through health culture and of the expected norms which accompany each stage. The concept of being moved on
through health culture is also an unknown, unarticulated process that is not conveyed to patients. This is a taken-for-granted process by health professionals, where nurses actively assist in moving patients through the various levels of the health care system whilst reinforcing normative culture.

One patient explained that he attended rehabilitation because

... the nurses are so good to you. You can’t always have them making suggestions and not meeting them half way - I know it won’t help though, I’ve tried it all before.

In prior discussion, MR’s experience when she was designated as a ‘psych consult’ were recounted. The consequence was that the nurses, who must have known her well as her stay in hospital was extensive, stopped bothering to care for her in the usual manner, thereby actively ‘moving her on’, which was also reinforcing society’s norms through the sub-conscious moving on process.

Similarly, nurses tend to express satisfaction towards notions of rehabilitation, empowerment and normalisation, perceiving these outcomes as an achievement and a positive change to aid patients to regain their sense of self. The patients still receive nursing if necessary (a professional decision), whilst the nurses seek to empower the patient towards self-care. Normative needs are met, (those prescribed by the profession, Bradshaw, 1972) and so whilst nurses ideologically talk about holistic care and patient centred nursing, in reality, nurses normalise patients’ expressed needs.

**Ways of Nursing and the Experience of Patients**

The generalisations that are consistently revealed in the ethnography, suggest that the power of culture and of the need to be obliging, to fit in, means that patients are generally passively compliant. Patients needs are their dominant reality yet these are not central to nursing practice. Nursing reinforces the dominant ideology of cultural norms whilst aiding patients through health culture and in meeting their needs. This section therefore re-looks at nursing practice and the implications of being a patient.

**Ways of nursing**

The ethnography has illustrated the role of nurses in eliciting and reinforcing compliance as the expected norm of society and employing institutions. Nurses perform certain actions for certain patients in a given time frame, as illustrated by
their allocated workloads and nursing plans. The way nurses work and carry out nursing regimes was found to be quite different, dependent on the reason a person nursed. ‘Someone Special’ in the chapter Patients’ Voices conveys a certain manner of nursing. The concept of the ways in which nurses work is of fundamental significance to the patient’s experience of illness, as illustrated in the following fieldnotes that were reflections on nursing care to a group of patients by two different nurses. They have been presented, in part, in the Patients’ Voices, but are now contrasted to present another perspective about ways of nursing.

Speed is of the essence - the patient said she tried to be ready; tried not to hold things up. This is not negated by the nurse, and there was a general sense of continual hurrying, whilst the nurse seemed to listen ... Speed continued as a dominant theme.

At times the impression was different. Nurses waiting, listening encouragingly to the stories about patient’s lives and how problems occurred. Tasks were completed without an air of speed and efficiency. There were no issues of dominance, just quiet suggestions and a comfortable rapport.

The nurse knew the patient and routine, but did not proceed automatically. They followed the patients lead, respectful of how the patient felt at the time, asking questions about what the patient would like. Patient individuality and respecting their mood was reflected as a two-way process rather than either person taking the initiative.

The conclusions that can be drawn from these ways of nursing, reinforce the power differential and the importance of appreciating that this is innate in nursing relationships. Nurses have the funding, shape the cultural norms and are in control; patients have needs and are expected to be compliant. In looking at the nurse-patient relationship and knowing that “… one person’s behaviour toward another is a controlling factor in the behaviour of another person” (Jourard, 1971, p.181), it is timely then to pause, to seek to understand the implications for patients.

To understand the implications for patient, however, suggests we firstly need to understand why so many nurses enacted regimes on patients.

**Body language and silence**

Interpersonal behaviour patterns are acquired as a means for satisfying needs and for reducing anxiety. Rigid interpersonal behaviour [termed ‘character armor’] ... serves the function of stifling spontaneity in the person and protecting the nurse from possible hurt coming from the outside, [thus serving as an acquired means of coping] (Jourard (1971, p 180)
Jourard argues that a latent function of the bedside manner is to reduce the probability of the patient expressing emotions, thus excluding the possibility of patient’s verbal responses to treatment and accordingly, verbal disclosure of what is on their mind. This suggests that the nurse’s caring, efficient manner and the doing of intimate procedures as though nothing different is occurring, makes it difficult for the patient to express feelings, thus decreasing the possibility of the patient responding to the nature of the procedure.

When nurses talk about healing and caring it is accepted as the intent, the whole purpose of nursing. The patient’s perspective reveals a rather uncomfortable discordant notion of patients being compliant and complementing the nurses as a means of having their needs met. The nurse’s manner lays the foundations for the basis of the interpersonal relationship yet nursing was seen to actively exclude the patient. When the nurse is not authentic, when she sets up the situation where a patient can’t realistically fully disclose themselves, then nurses hamper their own healing and therapeutic endeavours. It also follows that in repressing, refuting or stifling a person’s phenomenal world, nurses repress and suppress patients’ reactions and behaviours, replacing them with a rigid role definition and limited concept of self.

They behave as they “should” behave and feel what they “should” feel (Jourard, 1971, p.183).

The use and abuse of language

Paternalism is inherent in the medical model of health where the nurse-patient interaction takes place. It has been established that nurses and patients attach vastly different meanings to the perceptions of what occurs when they enter the health care system. Likewise, patients and nurses also attach different meanings to the language of participation, negotiation, and empowerment, despite the significance of these terms in the context of nursing actions and interactions. These words have similar connotations to choice. To be empowered, to negotiate and to participate, all imply that the patient understands their illness or deficit, that they understand their options and what is possible, and that they believe they really do have a choice.

Ashworth et al. (1992), Jewell (1994) and Kitson (1988,1992), are a few of the nursing scholars who draw out the distinction between professional and lay meanings. Participation is about both parties interacting with a common awareness. Caring is about choosing to actualise and develop the human capacity of feeling for and understanding another’s situation. The notion of choice implies the relationship
between the two people is embedded in respect. Patients can only truly participate when they understand, know what is possible and don’t feel they will be penalised later, for negotiation is really about power and control (Morris, 1991). Ashworth et al. (1992, p.1432), suggest that if nurses continue to make assumptions such as “… the common sense assumption that other individuals are people who exist like ourselves and that they perceive the world in a similar way” then nursing is and will remain paternalistic.

**Finding some meaning for patients?**

In reinforcing these regimes and seeking a positive motivation from patients, I accept that nurses perceive the movement back towards independence as positive because they care for the patient, but still, this questions the role of the nurse, who is reinforcing cultural norms rather than focusing on patients’ values as central to practice.

Do nurses superimpose their satisfaction onto the patient, or do they seek to understand what the implication is for the patient and what this may be seen to infer? How do patients accommodate all this? Do they understand what it implies? How difficult is it when the nurses also ‘hand the body back’ and expect the patient to be pleased? Do nurses, as the service provider, think about such abstract notions?

How do patients internalise experiences when they are treated as a non-thing, dehumanised, receive less care, are treated roughly, when their opinions and needs are ignored or regarded with contempt? How do nurses, who espouse holistic patient centred care, explain patients’ fears of being labelled as dominating, interfering or obsessed with their illness?

**Nursing from a position of power as the cultural norm**

By confirming their status as professional helpers, nurses imply they know what is best and will guide the patient in this direction (Jourard, 1977; Illich, 1977). Thus, whilst the nurses did not set out to use power over patients, patients were very aware of the imbalance in the nursing relationship. Kramer argues that to be care givers and to talk about humanism means nurses can’t continue to accept this detached power position (1990). To expect patients to believe you know best and do as they are requested due to your expert nursing knowledge (whilst believing this is selfless and caring), is incongruent with the moral intent implied within the word care (James, 1992). To nurse with respect for the patient as a human being, accepting and respecting their person, values and lifestyles is reflective of a reciprocal relationship
when two people meet. In this manner, nursing becomes professional and autonomous as nurses risk their sense of self and the good nurse image, as the other person (the patient), is of greater significance than the nurse’s personal needs. As Chrisman points out, care requires the care giver focus on the subject of care - the patient. To do this, the patient’s lifestyle, health status and values must be appreciated from their perspective (1982, p.118).

The implication for nursing is to understand and respect the effects of the power differential between the patient and the nurse, and the way in which culture both shapes nursing practice and oppresses the patient’s subjective experience. In appreciating this, nurses in all facets of practice can then value the nurse-patient relationship by understanding how patients have become so vulnerable, and therefore, how this impacts on the nursing relationship. If, by default, nurses are in a position of power, and they continue to espouse humanism and care, then they must understand and respect this position and seek to understand how patients have become so unwittingly oppressed. Illich (1977) urges nurses to understand the culture construction of the position within which they operate to appreciate how this power imbalance insidiously exposes patients to compliance. If nurses accept patient cues, this demonstrates respect for persons, which aids the patient to manage social boundaries and private space or, at the very least, to maintain a sense of being in control. When they understand, there is the possibility of change.

**Returning to Theory and Respect for Persons**

Whilst coming to understand why medicine dominates and shapes practice, the ethnography also reveals that patient subordination is the expected norm of the medical paradigm. Nursing is a profession under medical dominance, but that does not imply nurses must perpetuate that same paternalistic objectification in their relationship with patients. At the same time, the ethnographic dialogue draws attention to the discursive nature of common or folk language in nursing culture that refers to ‘other’ people, who are ‘patients’, where nurses ‘provide’ for these people; language alluding to notions of power and dependence.

Nursing literature is saturated with attributes of the caring nurse (Brown, 1986; Poole & Rowat, 1994). Nurses cared, but all the caring attributes could not alter reality, where nurses work with patients in a given bureaucratic framework embedded within the dominant health care hierarchy. Whilst nurses demonstrate the attributes of care, this does not imply a patient’s values are central to practice as a moral imperative. It does not alter the fact that the nurse does not even realise how nursing procedures
and the broader construction of practice, which is conveyed to patients, injure a patient’s sense of self. It also means that nursing needs to look beyond its own positive attributes and draw on the patient’s experience, challenging nurses to accept the position that patients have rights. Caring alone is not a satisfactory concept and does not imply respect for persons or notions of humanity when the nurse and the patient meet (Hall, 1993; Taylor, 1994).

Paterson and Zderad (1976) explain that nursing is about the nurse, the patient, the action and, most importantly, the essential character of the situation - ‘the between’. Whether the nursing act is verbal, manual, some degree of inter-subjectivity is involved; described as the nurse’s active presence of ‘being with’ or ‘being there’.

To ‘be with’ in this fuller sense requires turning one’s attention to the patient, being aware of and open to the here and now shared situation, and communicating one’s availability (Paterson and Zderad, 1976, p.14).

The Implications for Nursing and District Nursing

As the description and analysis are based on data gained from a rural district nursing service, the research therefore has direct implications for district nursing, offering an explicit insight into practice. There have been three ways of understanding that have evolved, that are specifically relevant to district nursing, and also, it is argued, to nursing per se. At the same time, understanding about the ways nurses practise and patient-nurse interactions has common implications for nurses and nursing practice in general. The cultural norms, cultural insight and the pathway through health culture are transferable from the implicit assumption grounded in the methodological and ethnographic notions of generalisation.

These ways of understanding are:

• Description of the mundanity of nursing practice and of being a patient in the context of district nursing in a rural area of Australia, represents an archival record.
• Secondly, a descriptive record brings into view the contextual issues that shape nursing practice, and patients’ feelings about being nursed, to reveal cultural knowledge about the expected norms of being a nurse and a patient. In turn cultural knowledge raises awareness of the many taken-for-granted ways of practice that were found to be contrary to patient’s needs and values, rather, they exemplify cultural norms.
Finally, the thesis describes the pathway through health culture so that the taken-for-granted and expected patterns are made clear for participants. This provides nurses with insight into the structure of practice and the manner in which nurses perpetuate this structure, enabling nurses to reflect on what they actually do.

The understanding gained through the research and made clear throughout the ethnographic text, challenges nursing to return to the espoused philosophical underpinnings of humanistic practice. As nurturers, nurses can choose a non-medical image; we can choose to work in different ways; ways that we already espouse, but that the power constructions of institutions tend to inhibit. Liaschenko (1994) highlights specific implications of the research for district nursing due to current day policies which focus on moving nursing back into peoples homes. Liaschenko suggests that as ‘sickness’ moves back from centralised institutions such as hospitals, as the spaces change, many of the pre-existing power structures which shape nursing practice will be absent. The challenge for nurses, she suggests, is not to unwittingly transfer the landscape of the hospital into the home, but to value the home as the patient’s private domain and to value what nurses do, through a nursing gaze.

If nurses can see through the cultural norms that have historically shaped nursing, nurses have the opportunity to practice with patients and to truly address the phenomena of being a patient and quality of life issues from patients’ perspectives. The nursing gaze returns to the notion of humanism and the possibility of nursing when patients and their individual values are central to nursing practice. Similarly, my personal situation in this thesis, suggests that district or home nursing, and nurses as women who are invariably integrated within communities, have a special and all encompassing insight into peoples lives. This insight provides nurses with the opportunity of unique privileged access which can enhance the humanistic base of their nursing practice.

Conversely, I remain concerned that, with diagnostic related groups and prescribed funding, more and more nursing will move into the home environment. On one hand, this offers nursing a unique opportunity but conversely, if funding is not increased correspondingly, who will receive the nursing in the home? If nurses accept the prestige of high technological care at the expense of humanistic pursuits, then patients who are marginalised because they don’t fit the desired image are (yet again) at risk. What will become of those patients described in this study and where will they be located in a society and profession that espouses care?
The Hermeneutic Circle of Knowledge Acquisition

Pursuing the hermeneutical circle of knowledge acquisition, the study commenced in a very personal, discursive place, grounded in the autobiographical experience as a nurse and a patient. The underlying tensions from my career and experience as a patient confronted my belief of a conflict in nursing practice, between what ought to be, grounded in humanistic philosophy, and what I perceived reality to be, from the contention that nursing ought to appreciate the experience of patients, as those who are the primary focus of care.

The ethnographic narratives revealed many patients and nurses who cared deeply about each other, sharing reciprocal relationships. It also revealed that no matter how much nurses care, nursing practice is consistently shaped by the norms of culture, overriding humanistic underpinnings. The norms of culture shape interactions in a community. The dominant norm is the medical paradigm, equating with compliance and cure and, therefore, those who can not meet this norm, those with chronic, degenerative malignant conditions, injuries and disabilities, are very vulnerable and marginalised.

Cultural norms permeate everything about being a patient. How a patient is seen is a social construction; more about who the patient is in the community’s social hierarchy than their nursing needs. Likewise, even the accepted mode of entry, the assumed role of nurses in people’s private lives and private bodies, occurs in a discreet manner as if it is not occurring. In effect, this sustains a level of privacy and yet it occurs without spoken understanding, only with assumed consent. On one hand, I appreciate the level of privacy and normality nurses conveyed, whilst simultaneously, I am reminded of the institutional scenario where entry is assumed consent. Further to this I came to appreciate how nurses lay the foundation for the patient-nurse interaction and that the manner excludes the patient from speaking about what is actually occurring. This is then compounded when patient’s do not speak up because they are vulnerable.

It seems as if this project has turned a full circle, as I return to the notions of needs and vulnerability yet again. I remain concerned by the oppositional notions within practice, yet now I can appreciate the power of culture in constructing nursing practice and, hence, why nurses reinforce cultural norms whilst patients submissively accept compliance as an expected norm. I hope that understanding what occurs in practice and why it occurs, will enhance the possibilities of change.
Anthropology demonstrates the ease with which the dominant culturally accepted norm oppresses subjective realities. To oppress another is simply not to accept or to put down, their living reality. Everyday living is deeply rooted in public culture. You either meet the cultural norm or you are ostracised (Carrington, 1998).

**Summary**

As an anthropological study, the intent of exploring the patient’s experience of nursing was to understand the cultural norms and the roles we undertake. In accepting the position that we are all participants within the culture and that people are inherently of equal worth, we can see how dominance shapes and gives meaning to the experience of others, and in turn, oppresses that group. Understanding may incite never ending questions, yet it also offers an enhanced appreciation of the what it means to be a patient, why patients are compliant, and how patients are so subtly silenced. *Knowing offers the potential for the private to be the political simply by putting into practice the value of every person as inherently being of equal worth; and by being consciously aware of how nurses set and control the agenda. Nurses can then revisit the way they practice from a simple beginning of listening and hearing what patients are seeking to convey.*

The writings of Robert Coles reinforce much of what has been said in this thesis, as he reflects on his career in medicine, psychology and English literature. Through his own story, Coles explores the value of listening to patients’ stories, as they tell us so much about a person’s life and experiences, and the meaning they attach to these. In a note of caution he reminds us that, as professionals, we need answers to questions and so we shape the answers by the wording of the question and the story is limited to the questions. We have a clinical history, personal history, family history and phrases that de-compartmentalise their histories to be interpreted and retold second hand. Coles urges helping professionals to take care, to listen carefully and to regard each story with due respect.

> The people who come to see us bring their stories. They hope they tell them well enough for us to understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember what we hear is their story (Coles, 1989, p.7).

The culture in which nursing takes place is so very complex, with nurses and patients subject to broader cultural norms. In coming to understand the mundane ways in which nurses, as individuals and as a united group, do construct their own practice and the realities experienced by patients, they have the opportunity to accept nursing
on its own terms and to listen to patients. When patients trust a nurse with their story they trust them with its interpretation. Likewise, understanding patients’ experiences and daily realities enables one to have, and to offer, insight. Understanding how culture constructs practice enables nurses to re-evaluate what is occurring, if they choose to be caring in the moral sense and accept patients as central to practice.
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Appendix 1: CONSENT FORM ................................................................. 2
Appendix 2: PLAIN LANGUAGE STATEMENT ........................................... 3
Appendix 3: SAMPLE INTERVIEW GUIDE ................................................ 4
Appendix 4: EXAMPLES OF ANALYTIC TABLES ........................................ 5
4.1 The Broad Cultural Landscape ........................................................... 5
4.2 Delivery of Nursing Care ................................................................. 6
4.3 Basic Nursing Care ........................................................................... 7
4.4 The Nurse, The Patient, The Issues .................................................... 8
4.5 Kinds of Patient’s - The Nurses’ View ............................................... 9
4.6 Kinds of Nurses - The Patients’ View ............................................... 10
4.7 Ways of Nursing 1 ......................................................................... 11
4.8 Ways of Nursing 2 ......................................................................... 12
4.9 The Social Construction of the Patient Interaction ............................. 13
APPENDIX 1: CONSENT FORM

I...........................................................................................................................

of...........................................................................................................................

here by consent to participate in a research study to be undertaken by Janet Hall. I understand the purpose of the research is to describe district nursing from the perspective of the nurses, the actions of nursing and the experience of being a patient.

I acknowledge that

1. upon receipt, my questionnaire will be coded and my name and address kept separate;

2. any information that I provide will not be made public in any form that could reveal my identity to an outside party: it will remain anonymous;

3. aggregated results of the whole study only will be used for research purposes and may be reported in scientific academic journals;

4. individual results will not be released to any person except at my request and on my authorisation;

5. I am free to withdraw my consent at any time, in which event my participation in the research study will immediately cease and any information obtained destroyed if requested by me.

Signature: ................................................. Date: .................................
APPENDIX 2: PLAIN LANGUAGE STATEMENT

As a nurse researcher, I am interested in studying the actions and interactions which occur during everyday episodes of care, to persons receiving visits from nurses who are employed by a district nursing service. The study will look at the structure and organisation of the nursing service, the physical procedures the nurse carries out, observing and recording patient-nurse interactions and conversations. This will be done only by myself (Janet Hall) and confidentially recorded. Each participant will have a code number to maintain their privacy, whilst I will have corresponding names and addresses which will be kept separately in a locked cupboard.

When I finish the research, or after your discharge from the district nursing service, I will interview you, the nurse or nurses who provided the service and, if appropriate, others who helped care for you. Each interview will be conducted separately, and all information will be totally confidential. Some quotes may be used to illustrate findings. To maintain your privacy these will not be associated with either names or codes, and will only be part of the total report.

The questions will be informal and you only need to answer as you feel comfortable. The aim of these is to listen to the person who is the client, the nurse, and others directly involved in your care, in an attempt to understand the experience from all these participants. I anticipate each interview would take about ten minutes.

As explained in the consent form, no individual information will be released in any way, but will be put together to form a picture of a district nursing service and the patients’ experience. This will then form a report which will be available from the participating organisation.

As stated on the consent form, you are free to withdraw consent at any time, even during the final interview.

Thank you for taking the time to read and consider this - any questions are welcome.

Yours Sincerely,

Janet Hall

Supervisor: Helen Cox,
Senior Lecturer Deakin University
Contact: 03 9522 72756
APPENDIX 3: SAMPLE INTERVIEW GUIDE

[Explain the purpose of the interview - there are no right or wrong answers, as the study seeks to elicit their opinions and experiences. Reiterate my background, and the purpose of the interview; clarify anonymity, confidentiality and that the participant may interrupt or withdraw consent at any time. Explain why I am using a tape recorder, check they are comfortable with this and ready for the tape recorder to be turned on. (NB This is the researchers guide only. DN stands for district nurse.)]

I’d like to get your ideas about what occurs when the DN comes to visit.

Can you describe to me what you do from the time the DN arrives till the time they leave.

Can you describe to me what the DN does from the time they arrive till they leave.

What difference does the DN’s visit make for you?

What other differences could the DN visit make for you?

What kind of interactions occur between yourself and the nurse?

What was most significant for you as a patient with this district nursing service? What else was significant? (Repeat as often as responses are forthcoming)

Has anything happened concerning your care that has been particularly important to you? Has anything else? (Repeat as often as responses are forthcoming)

Have you received any nursing that you felt was not as you would have liked? (Repeat as often as responses are forthcoming)

Has any thing struck you as being particularly impressive about the care that you received from the DN service? Are your expectations and nursing needs being met?

[Thank participants for their time and contribution to the research.]

[The prompt questions ought to elicit information about the process and outcomes of care provided by the district nurses from patients’ perspectives. They are adapted from Spradley (1980) and Norman et al. (1992), which drew on Flanagan’s critical incident technique. Both contain structured and contrast questions to elicit similarities and contrasts; and positive and negative aspects, as part of ethnographic description. A critical incident is any incident which is critical to the patient.]
APPENDIX 4: EXAMPLES OF ANALYTIC TABLES

4.1 The Broad Cultural Landscape

<table>
<thead>
<tr>
<th>Government Policy</th>
<th>Funding and Policy</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The nursing unit</td>
<td>Reinforce policy direction</td>
<td></td>
</tr>
<tr>
<td>Charge Nurse</td>
<td>Allocation of scarce resources</td>
<td></td>
</tr>
<tr>
<td>“District Nursing Service” 10 female nurses rostered on a dedicated basis to form this service.</td>
<td>Make decisions on the funding allocation to meet hospital / government policy that is already dictated</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Who gets what care?</td>
<td>Doctors and hospital “order nursing”</td>
</tr>
</tbody>
</table>

**Apportioning of workload**

- Time
  - Difficult patients
  - Heavy patients
  - Type of nursing required
  - Personalities
  - Causality
  - Distance

**Amount of care agreed on**
- related to above -
- plus informal nurses private time
4.2 Delivery of Nursing Care

Delivery of Nursing Care - Structural analysis

Daily routine generalised
- Organisation and get ready
- Listen for overnight messages
- Check book
- Get the nursing notes
- Get equipment
- Check equipment in the car

Travel
- To next patient
- Think & reassess
- Treatment
- Make decisions

Delivery of nursing
- Arrive
- Read notes
- Enter
- Meet the patient
- Organise
- Talk - listen

Nursing procedures
- Assess
- Support
- Educate
- Do for

Additional procedures
i.e. Medication

Tea breaks
- Have a break

Communication
- Nursing stories
- Personal stories
- Listen
- Support
- Humour
- Black humour

Documentation
- Official nursing notes
- Hospital, unit stats. & accounting
- Liasing with family medics, others
- Informal oral communication

Tidy Up
- Restock car
- Organisational time
- Informal extras
- Tidy up
- Convert case load & apportion workloads

Closure
- Official nursing notes
- Documentation for hospital, unit stats. & accounting
- Liasing with family medics, others
- Informal oral communication
- Hand over

On going Assessment
- Physical
- Mental
- Emotional

Other tasks
- Close curtains
- Get books
- Wash glasses
- Hand meal

Informal & formal communication
- Re - patients
- Interpersonal
- Informal
4.3 Basic Nursing Care

Basic nursing care structural analysis

- Greeting → Entering a home
- Communication → Finding the patient
  - Saying hi and who you are
- Organisation
  - Assessment → Talking to Listening & Responding
  - Procedure/s
  - Tidy up
  - Closure
- Collect equipment
  - Dispose of
  - Prepare area do procedure
  - Assist patient
  - Encourage self
  - Educate
- Direct & ongoing cleanliness
- Physical agility
- General health
- Mood
- Close the conversation yet leaving it open
### 4.4 The Nurse, The Patient, The Issues

<table>
<thead>
<tr>
<th>The Nurse</th>
<th>The Patient</th>
<th>Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse enters</td>
<td>Who is it today</td>
<td><strong>Timing</strong>&lt;br&gt;Does this fit in with their day?&lt;br&gt;Do they sit waiting?</td>
</tr>
<tr>
<td>Greeting exchange</td>
<td>Personal welcome neutral - negative</td>
<td><strong>Intimate private nature of nursing</strong>&lt;br&gt;Is the person treated with respect?&lt;br&gt;Intimate private acts of nursing performed with respect?&lt;br&gt;Individuality of their feelings accepted with respect?</td>
</tr>
<tr>
<td>Communication</td>
<td>Do they listen accept, neutral, negate?</td>
<td><strong>Adjustments:</strong>&lt;br&gt;• To needing nursing&lt;br&gt;• To nurses in their home&lt;br&gt;• To loss of privacy&lt;br&gt;• To different nurses&lt;br&gt;• To being directed within their home for intimate activities</td>
</tr>
<tr>
<td>Get ready for procedure</td>
<td></td>
<td><strong>Aware of the patient’s broader life</strong></td>
</tr>
<tr>
<td>Do procedure</td>
<td></td>
<td><strong>Equity of treatment</strong>&lt;br&gt;<strong>Equity of access to treatment.</strong></td>
</tr>
<tr>
<td>Meet patient needs</td>
<td></td>
<td><strong>The amount of treatment</strong>&lt;br&gt;<strong>Dependency</strong></td>
</tr>
<tr>
<td>Assessments</td>
<td>Were there other needs&lt;br&gt;Were they attended to or referred on?</td>
<td></td>
</tr>
<tr>
<td>Act on assessments</td>
<td>Did the nurse see the broad picture. Organise and liaise with others?</td>
<td></td>
</tr>
<tr>
<td>Tidy up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closure</td>
<td>Does the patient feel their needs were met, respectfully &amp; adequately.</td>
<td></td>
</tr>
</tbody>
</table>
### 4.5 Kinds of Patient’s - The Nurses’ View

<table>
<thead>
<tr>
<th></th>
<th>Easy patients</th>
<th>Others</th>
<th>Difficult patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepting and /or compliant</td>
<td>Wish to be involved in their treatment</td>
<td>Fight being controlled</td>
<td></td>
</tr>
<tr>
<td>Are ready if this is possible</td>
<td>Are not ready and waiting</td>
<td>Non compliant and will not be waiting</td>
<td></td>
</tr>
<tr>
<td>Congenial personality</td>
<td>‘Difficult’ personality</td>
<td>Non compliant or difficult personality</td>
<td></td>
</tr>
<tr>
<td>Social status</td>
<td>Make requests that do not fit with the routine</td>
<td>Low social status or this is a non-issue</td>
<td></td>
</tr>
<tr>
<td>Don’t ask for extra nursing time</td>
<td>Require a high level of resources</td>
<td>May have caused their illness i.e. alcohol</td>
<td></td>
</tr>
<tr>
<td>Don’t complain</td>
<td>Live a distance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speak highly of the nurse</td>
<td>Require a high level of resources</td>
<td>May still be eternally grateful for any assistance</td>
<td></td>
</tr>
<tr>
<td>Appreciate what is done</td>
<td>Not always glowing about the nursing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are always grateful</td>
<td>Not eternally grateful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accept directions</td>
<td>Are not ‘easy’ nursing</td>
<td>Don’t try and help themselves</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Do not blindly follow nurses directions</td>
<td></td>
</tr>
</tbody>
</table>
### 4.6 Kinds of Nurses - The Patients’ View

<table>
<thead>
<tr>
<th>The Good Nurse</th>
<th>Neutral</th>
<th>The other nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arrives on time</td>
<td>Patients simply accept and or expect what occurs</td>
<td>Arbitrary about their timing</td>
</tr>
<tr>
<td>Listens</td>
<td></td>
<td>No explanation</td>
</tr>
<tr>
<td>It matters to her personally</td>
<td>Socially conditioned to being a patient</td>
<td>Nurses for another reason</td>
</tr>
<tr>
<td>Takes special care</td>
<td></td>
<td>Pre-empts and overrides patient's moves</td>
</tr>
<tr>
<td>Does some extras</td>
<td>Too unwell or emotionally tired to participate</td>
<td>Rough, slap dash</td>
</tr>
<tr>
<td>We work together/ they take time /patient led</td>
<td>The good obliging patient, knowing who they will need in the future</td>
<td></td>
</tr>
<tr>
<td>Knowledgeable and efficient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talks with you</td>
<td></td>
<td>Talks at you</td>
</tr>
<tr>
<td>Gives of herself</td>
<td></td>
<td>Ritualistic</td>
</tr>
<tr>
<td>Takes initiative and acts on it</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Variables:**
- Type of nurse
- Type of patient
- Socialisation
- Current need
- Future need
### 4.7 Ways of Nursing 1

<table>
<thead>
<tr>
<th>The Good Nurse</th>
<th>Foci patient</th>
<th>Foci Self</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance of patient list</td>
<td>Questions for continuity of care</td>
<td>Questions</td>
</tr>
<tr>
<td>Acceptance of waiting</td>
<td>Questions “balancing out” if it decreases quality time with patients</td>
<td>Questions “balancing out” if it means an increased workload</td>
</tr>
<tr>
<td>Structured, task orientated</td>
<td>Acts to provide care in line with patient’s needs</td>
<td>Creativity benefiting self</td>
</tr>
<tr>
<td>Routines adhered to</td>
<td>Creativity and lateral thinking to meet patient needs</td>
<td>Manipulating for self or patient</td>
</tr>
<tr>
<td>Routine procedures adhered to</td>
<td>Listens</td>
<td>Listens acts only if self benefit</td>
</tr>
<tr>
<td>Seeking behaviour</td>
<td>Reacts to patients</td>
<td>Routines &amp; rituals</td>
</tr>
<tr>
<td></td>
<td>Nurses to meet patient’s needs</td>
<td>Nurses to meet legal requirements</td>
</tr>
</tbody>
</table>

**The line is blurred dependent on numerous variables**

- The reason a person is nursing: Nature of a patient’s request
- Constraints on practice imposed by hospital policies / funding / law: Knowledge base
- Type of education (apprentice or tertiary trained): Ability to be creative and lateral
- Exposure to models of nursing: Support or otherwise from the employing body
- Previous life and nursing experiences
4.8 Ways of Nursing 2

<table>
<thead>
<tr>
<th>Vocational</th>
<th>Work for the income</th>
<th>The Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide assistance beyond the call of duty</td>
<td>Provide ordered nursing</td>
<td>Patient centred nursing</td>
</tr>
<tr>
<td>See themselves helping a person less fortunate</td>
<td>See themselves as doing a job</td>
<td>- will do extras if a need is seen</td>
</tr>
<tr>
<td>(Pity)</td>
<td>(Pity)</td>
<td>Money is important but not everything</td>
</tr>
<tr>
<td>Follow doctors orders or seek orders</td>
<td>Follow orders</td>
<td>Equality</td>
</tr>
<tr>
<td>Subservience</td>
<td>Do not want to “rock the boat”</td>
<td>Assesses, makes judgements, liaises and acts</td>
</tr>
<tr>
<td>Ritualistic practice</td>
<td>Ritualistic practice</td>
<td>Autonomous</td>
</tr>
<tr>
<td>Seek hierarchy</td>
<td>Accept hierarchy</td>
<td>Creativity</td>
</tr>
<tr>
<td>Do for</td>
<td>Do for</td>
<td>Acknowledges hierarchy - works ‘around’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Does with</td>
</tr>
</tbody>
</table>

FIGURE 9
4.9 The Social Construction of the Patient Interaction

- The type of nurse and way of nursing (moving from Vocational towards Professionalism)
- Dependency (either emotional or physical) specifically related to limited patient options and intimate procedures
- How a patient wants to be perceived: holistically or an isolated incident (Ong, 1991)
- Social conditioning and enculturation
- Social status in the community
- Legitimacy of needs, Social conditioning, Enculturation, Medical Model
- Type and legitimacy of illness