Patients’ and carers’ views of quality palliative and supportive district nursing care

A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy in the Faculty of Medical and Human Sciences

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Contents

Table of contents 2
List of tables 7
List of figures 8
Abstract 9
Declaration and copyright statements 10
The author 11

Chapter 1  Introduction

1.1 Introduction 13
1.2 Philosophical underpinnings of this thesis 13
1.3 Definitions 14
  1.3.1 Palliative and supportive care 15
  1.3.2 District nursing 18
  1.3.3 Patients and carers 19
  1.3.4 Quality care 20
1.4 Healthcare policy and philosophy: an overview 21
  1.4.1 National healthcare policy 21
  1.4.2 Palliative and supportive care policy 22
  1.4.3 Community palliative and supportive care: policy and choice 26
1.5 Layout of thesis 27

Chapter 2  Theoretical positioning

2.1 Philosophical positioning 28
  2.1.1 Reforming power 28
  2.1.2 Power/knowledge: a post-structuralist understanding 29
  2.1.3 Power as subject formation 31
  2.1.4 The necessity of the other but the rejection of the material 33
  2.1.5 Relation to this thesis 33
2.2 Theorising a post-structuralist quality of care 34
  2.2.1 What is a moral action and how can one be recognised 34
  2.2.2 Is a moral action indicative of quality care? 36
  2.2.3 Theorising moral practice in palliative and supportive care 36
  2.2.4 The limits of post-structural morality in palliative and supportive care 38

Chapter 3  Literature review

3.1 Introduction 40
3.2 Quality of care 41
  3.2.1 Temporal effect on quality of care 41
  3.2.2 Perspectives and their affect on defining quality of care 42
3.3 District nurses and palliative care 47
### Chapter 4  Methods: underlying theoretical considerations

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Summary of research question</td>
<td>79</td>
</tr>
<tr>
<td>4.2 Introduction</td>
<td>79</td>
</tr>
<tr>
<td>4.3 Sampling</td>
<td>81</td>
</tr>
<tr>
<td>4.4 Data production</td>
<td>83</td>
</tr>
<tr>
<td>4.5 Morality of production</td>
<td>84</td>
</tr>
<tr>
<td>4.6 Consent</td>
<td>86</td>
</tr>
<tr>
<td>4.7 Data production tools</td>
<td>87</td>
</tr>
<tr>
<td>4.7.1 Observational methods</td>
<td>88</td>
</tr>
<tr>
<td>4.7.2 Interviews</td>
<td>88</td>
</tr>
<tr>
<td>4.7.3 Diaries</td>
<td>90</td>
</tr>
<tr>
<td>4.7.4 Comparing diaries, interviews and observational methods</td>
<td>91</td>
</tr>
<tr>
<td>4.8 Data analysis</td>
<td>91</td>
</tr>
<tr>
<td>4.8.1 Thematic analysis as observed in grounded theory</td>
<td>93</td>
</tr>
<tr>
<td>4.8.2 Discourse analysis</td>
<td>94</td>
</tr>
<tr>
<td>4.8.3 Use of qualitative analysis software</td>
<td>97</td>
</tr>
<tr>
<td>4.8.4 Combining thematic analysis with discourse analysis</td>
<td>97</td>
</tr>
<tr>
<td>4.9 Rigour and validity in post-structural research</td>
<td>99</td>
</tr>
</tbody>
</table>

### Chapter 5  Methods: How the study was conducted

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 Introduction</td>
<td>101</td>
</tr>
<tr>
<td>5.2 Study approval processes</td>
<td>102</td>
</tr>
<tr>
<td>5.2.1 Portfolio approval</td>
<td>102</td>
</tr>
<tr>
<td>5.2.2 Initial selection of research sites</td>
<td>102</td>
</tr>
<tr>
<td>5.2.3 Research ethics approval</td>
<td>102</td>
</tr>
<tr>
<td>5.2.4 Hospice approval</td>
<td>103</td>
</tr>
<tr>
<td>5.2.5 Consent</td>
<td>103</td>
</tr>
<tr>
<td>5.2.6 Sample size</td>
<td>104</td>
</tr>
<tr>
<td>5.3 Recruitment and sampling</td>
<td>104</td>
</tr>
<tr>
<td>5.3.1 Recruitment strategy</td>
<td>104</td>
</tr>
<tr>
<td>5.3.2 Research nurses</td>
<td>108</td>
</tr>
<tr>
<td>5.3.3 Recruitment packs</td>
<td>109</td>
</tr>
<tr>
<td>5.4 Data production</td>
<td>110</td>
</tr>
<tr>
<td>5.4.1 Adapting data production methods</td>
<td>110</td>
</tr>
<tr>
<td>5.4.2 Interviewing</td>
<td>111</td>
</tr>
</tbody>
</table>
Chapter 6  The paradox of busyness

6.1 Introduction 127
6.2 Timekeeping – known time and date, or only known data 127
6.3 Effects of timekeeping on quality of care 128
  6.3.1 Organisational requirements 129
  6.3.2 Prioritisation 133
  6.3.3 Laziness 135
6.4 Busyness as a paradoxical discourse 137
6.5 Busyness: becoming docile-patient, becoming immoral-nurse 140
  6.6 Moral district nursing care, becoming-other 144
    6.6.1 Becoming friend or relative 144
    6.6.2 Protecting the home 145
    6.6.3 Reshaping but remaining nurse 146
    6.6.4 Becoming counsellor 147
    6.6.5 Becoming younger – the thesis of morality 151
6.6 Summary 153

Chapter 7  Power/knowledge

7.1 Introduction 154
7.2 Extant discourses of knowledge on district nurses 154
7.3 Knowledge restricting action of district nurses 157
7.4 Reforming knowledge of district nursing services 158
    7.4.1 Equipment provision 159
    7.4.2 Psychosocial support 160
7.5 Imagining future care: viable yet immorally restricted subjectivities 166
    7.5.1 Care not directly linked to death and dying 167
    7.5.2 End of life care 169
7.6 Distributing knowledge 173
    7.6.1 District nurses 174
    7.6.2 Other healthcare staff 174
    7.6.3 Other written information 178
    7.6.4 Other patients and carers 180
7.7 Summary: structurally immoral care 181
9.7.5 What is district nursing – the patient and carer perspective
9.7.6 Interactions with the patient
9.7.7 Interactions with people other than the patient
9.8 Conclusion

References

Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix A</td>
<td>Glossary</td>
<td>269</td>
</tr>
<tr>
<td>Appendix B</td>
<td>Initial interview protocol</td>
<td>270</td>
</tr>
<tr>
<td>Appendix C</td>
<td>Data extraction sheet</td>
<td>273</td>
</tr>
<tr>
<td>Appendix D</td>
<td>Patient consent form</td>
<td>275</td>
</tr>
<tr>
<td>Appendix E</td>
<td>Carer consent form</td>
<td>276</td>
</tr>
<tr>
<td>Appendix F</td>
<td>Reply slip</td>
<td>277</td>
</tr>
<tr>
<td>Appendix G</td>
<td>Patient information sheet</td>
<td>278</td>
</tr>
<tr>
<td>Appendix H</td>
<td>Carer information sheet</td>
<td>280</td>
</tr>
<tr>
<td>Appendix I</td>
<td>Diary guide</td>
<td>282</td>
</tr>
<tr>
<td>Appendix J</td>
<td>Demographic details</td>
<td>283</td>
</tr>
<tr>
<td>Appendix K</td>
<td>Interview protocol second iteration</td>
<td>285</td>
</tr>
<tr>
<td>Appendix L</td>
<td>Interview protocol third iteration</td>
<td>289</td>
</tr>
<tr>
<td>Appendix M</td>
<td>Transcription confidentiality agreement</td>
<td>295</td>
</tr>
<tr>
<td>Appendix N</td>
<td>Coding for interview with P16 and C16</td>
<td>296</td>
</tr>
<tr>
<td>Appendix O</td>
<td>Summary of coding for all interviews</td>
<td>298</td>
</tr>
<tr>
<td>Appendix P</td>
<td>Excerpt of interview with coding stripes: P6 ‘future care’</td>
<td>299</td>
</tr>
<tr>
<td>Appendix Q</td>
<td>Overall coding structure</td>
<td>300</td>
</tr>
<tr>
<td>Appendix R</td>
<td>Coding structure for busyness</td>
<td>302</td>
</tr>
<tr>
<td>Appendix S</td>
<td>Memo of busyness</td>
<td>303</td>
</tr>
<tr>
<td>Appendix T</td>
<td>Diagram of busyness</td>
<td>304</td>
</tr>
<tr>
<td>Appendix U</td>
<td>Memo of ‘Timekeeping and prioritisation’</td>
<td>305</td>
</tr>
<tr>
<td>Appendix V</td>
<td>Memo of ‘Effects of busyness’</td>
<td>306</td>
</tr>
<tr>
<td>Appendix W</td>
<td>Coding structure for P3</td>
<td>309</td>
</tr>
<tr>
<td>Appendix X</td>
<td>Coding structure for P16</td>
<td>310</td>
</tr>
<tr>
<td>Appendix Z</td>
<td>Interview transcript for P7</td>
<td>311</td>
</tr>
</tbody>
</table>

Word Count: 69 562
# List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Literature review search strategy</td>
<td>51</td>
</tr>
<tr>
<td>3.2</td>
<td>Literature review data extraction table</td>
<td>53</td>
</tr>
<tr>
<td>4.1</td>
<td>Diary/interview comparison</td>
<td>92</td>
</tr>
<tr>
<td>5.1</td>
<td>Summary of demographic data</td>
<td>124</td>
</tr>
<tr>
<td>5.2</td>
<td>Comparison of national age ranges of district nursing case loads versus age ranges for this study</td>
<td>124</td>
</tr>
</tbody>
</table>
## List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Literature review process</td>
<td>65</td>
</tr>
<tr>
<td>5.1</td>
<td>Recruitment strategy phrases</td>
<td>107</td>
</tr>
<tr>
<td>5.2</td>
<td>Number of participants approached versus number of participants recruited</td>
<td>109</td>
</tr>
</tbody>
</table>
Abstract

The University of Manchester

Abstract of thesis submitted by Maurice Nagington for the Degree of Doctor of Philosophy and entitled: Patients’ and carers’ views of quality palliative and supportive district nursing care September 2012

Quality of care is conceptualised by professionals and in policy documents as: compliance with ‘best practice’ guidelines; improving satisfaction rates; fiscal efficiency; and ethical care. ‘Quality’ in palliative and supportive district nursing care has been conceptualised in all these ways. However, the empirical research in this area draws mostly on professionals’ and carers’ views with little research addressing patients’ views. With political rhetoric pushing for a ‘patient led’ NHS, research into how patients conceptualise quality in this area is necessary to both critique this rhetoric and/or facilitate its aims. Therefore, this research investigates patients’ and carers’ views on the quality of palliative and supportive district nursing care.

Participants were recruited to an exploratory qualitative study resulting in a convenience sample of twenty six patients (all of district nursing caseloads) and thirteen carers. All participants were over eighteen, able to consent, lived in their own homes, were under the care of district nurses, and had palliative care needs. Eighteen participants had a cancer diagnosis, six had a non-malignant diagnosis, one had co-morbidities, and one participant did not disclose their diagnosis. Semi-structured interviews were conducted with all participants, five participants were interviewed twice. Post-structuralist theories were used with discourse analysis techniques for the final analysis.

The findings identify three of the most influential discourses in relation to the morality and quality of care: Firstly, ‘busyness’, and how its performance by district nurses masks patients’ and carers’ ability to critique care, instead producing a pseudo-quality which fixes patients and carers subjectivities. Secondly, ‘power/knowledge’ and the ways in which it prevents patients and carers accessing care which they need, and altering care to suit their needs. Thirdly, ‘the home’ and how it (re)forms district nursing care and district nursing care (re)forms the home; meaning that actions by district nurses must also consider the impact on the home as well as the patients and carers.

In conclusion quality care may be produced by: ceasing to measure quality; involving patients and carers with commissioning and directing palliative and supportive care; supporting groups other than district nurses such as patients, carers and third parties to produce and distribute knowledge about district nursing care; increasing patients’ and carers’ ability to communicate with one another about their care.

Further research may investigate: how patients and carers with palliative and supportive care needs may be involved in commissioning; the most appropriate wording and means to distribute knowledge about palliative and supportive district nursing care; ethnographic work to explore how district nursing and the home interact; more detailed theorisation of how the material and the discursive can be accounted for within post-structuralism.
Declaration

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The Author

This section briefly sets out my clinical and academic experience to date with particular reference to how it influenced this thesis and the way in which the research was done.

Qualifications

2003 - 2006  University of Manchester

*BNurs (Hons) - 1st Class*

*Registered Nurse (Adult)*

*Fraser-Brockington Dissertation Prize*

2008  University of Manchester

Promoting Effective Practice in Palliative Care – (1st Class)
FHEQ Level 6 Continuing Professional Development Module

Background

During my undergraduate degree it became clear that my interests lay in palliative and supportive nursing care with my dissertation taking the form of a research proposal titled: ‘An exploration of the views of doctors and nurses on rehydration therapies in terminal heart failure patients’. My nursing career began on an acute medical ward with a focus on endocrinology. However, after one year I moved to work at St Ann’s Hospice to pursue my interests in palliative and supportive care where I undertook a post-registration qualification in palliative and supportive care.

Whilst I did not undertake a Master’s degree I did continue to read and develop academically after completing my undergraduate degree, becoming particularly interested in the works of post-structuralist authors. Foucault’s *The Birth of the Clinic* was the first such book that I read, and whilst it was an extremely difficult and challenging read, it opened my eyes to a new way of reading and understanding academia, and I developed a desire to apply such
an understanding to nursing. I then continued to read a wide range of literature, from ethics, moral philosophy, history, anthropology and sociology, sometimes just picking a book off the shelf in the library on my day off and reading a chapter. Some of this reading was directly related to nursing and some not. This fostered a desire to understand how disparate forms of academic thought and research could become relevant to healthcare practice and research; something that I have tried to achieve in the past three years writing and researching for this thesis and will continue to develop post-PhD.

To foster this interest I have attended the Nursing Philosophy conference presenting a paper based on chapter 2 in 2011 and chapter 6 in 2012 and the 4th Psychosocial studies network conference. In addition I have attended four summer schools: The Summer Institute in Qualitative Research in 2010 and 2011; Human Rights Older people and end of life care 2011; and The Sexuality Summer School 2012. These events all had an interdisciplinary focus and were often very theory driven, giving me the chance to understand how others had used and developed continental philosophy with empirical research. Importantly they were not all healthcare and/or nursing focussed. I have also regularly attended a wide range of seminars such as: discourse analysis, social anthropology, queer theory, nursing, and 20th century history. I also undertook formal research training with the School of Nursing, Midwifery and Social work as part of the training element for this PhD.

I would like to acknowledge The Dimbleby Cancer care trust and The University of Manchester’s Alumni fund for their generous funding of this PhD studentship.
Chapter 1

Introduction

1.1 Introduction

The aim of this introduction is to justify and give context to the research question: patients’ and carers’ views on the quality of palliative and supportive district nursing care.

The research methods used are grounded in the traditions of discourse analysis and grounded theory. However, neither of these methods are faithfully followed, instead they are re-read and adapted using post-structuralist theories.

Any terms which appear in italics are used with a specific theoretical meaning. Whilst these are explained within the thesis, for ease of reading a glossary of all italicised terms is provided in appendix A.

1.2 Philosophical underpinnings of this thesis

A full justifications and critique of the philosophical underpinnings is given in chapter 2. However, in order to understand the way in which the rest of this chapter is composed it is necessary to briefly outline the philosophical underpinnings to this thesis here.

The driving philosophical position underpinning this thesis is post-structuralism. It is a branch of philosophy which rejects that scientific methods can build an understanding about a single truth of what reality is and how society functions, and it rejects the idea of identifiable linear and hierarchical structures and developments. Instead post-structuralism speaks in terms of
how discourses connect, flow and influence one another in non-linear ways and is primarily concerned about how this occurs through language.

In keeping with this, post-structuralism encourages the resistance of firm definitions of concepts; instead opting for a deconstruction of ideas (Derrida and Spivak 1998). Whilst post-structuralism broadly accepts the need for concepts to have some stability when they are deployed through language as to have no stability would result in the cessation of any transfer and continuance of meaning an identity within social structures (Butler 1997a); it aims to critique concepts in such a way as to demonstrate the problematic nature of concepts. This can be achieved in a number of ways but is not limited to, historical analysis (Foucault 2002), literary analysis (Derrida and Spivak 1998) and empirical evidence that contravenes assumptions (Butler 1993). Post-structuralism as a whole therefore rejects any firm methods. Instead it operates as a broad philosophical underpinning to challenge definitions so that when reconstruction occurs (in this case through the process of data analysis) new understandings may be reached and the limits of those understandings better understood.

1.3 Definitions

Four key terms will be opened up and critiqued below: patients and carers, palliative and supportive care, district nursing and quality care. In keeping with post-structuralism the aim of this section is not to provide working definitions for the whole thesis but instead to demonstrate the slipperiness (Derrida and Spivak 1998) of even the key terms and open up possibilities for novel analyses. However, for recruitment to function it is necessary to place limits on the terms ‘patient and/or carer’, ‘palliative and supportive care’, and ‘district nurses’. To fail to do otherwise would result in an inability to identify anyone or anything, and recruitment would logically fail. Therefore, at the end of the deconstructions of these three terms a definition is given for the purposes of recruitment only. Beyond recruitment, progressing into data collection and analysis, the terms are allowed to become ‘slippery’. Quality of care is left
undefined as it does not affect the ability of the study to recruit participants in the same way as being unable to identify patients would.

1.3.1 Palliative and supportive care

The most widely quoted definition of palliative care, and the one used in this thesis as the definition to recruit patients in accordance with, is the World Health Organisations definition:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.” (Sépulveda et al. 2002: 94)

Such a definition of palliative care appears to incorporate understandings of ‘supportive care’:

“Supportive care is provided to people with cancer and their carers throughout the patient pathway, from pre-diagnosis onwards. It should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment. It encompasses: self help and support; user involvement; information giving; psychological support; symptom control; social support; rehabilitation; complementary therapies; spiritual support; palliative care; end-of-life and bereavement care.”
(National Council for Hospice and Specialist Palliative Care Services 2002: 2)

This definition shares the same aims of providing physical, psychosocial and spiritual support and is “fully integrated”; whilst palliative care aims to be “provided early in the course of the illness”. Therefore, if palliative and supportive care is fully integrated early into the course of the illness then there may be a mimetic slide occurring where supportive and palliative care ceases to be considered ‘supportive and palliative care’ and instead just becomes ‘good practice’ because it has become “fully integrated”. If this slide occurs in one direction then it may also occur in the opposite direction. It is possible that medical interventions previously reserved for curative purposes in the ‘early stages’ are beginning to be considered alongside palliative measures. There is evidence for this within the literature debating treatments which may have traditionally been used for ‘curative’ purposes being introduced into palliative care (Evers et al. 2002). Therefore, the philosophy of not aiming to prolong or hasten death and affirming death as a natural process, starts to become problematic when medical treatments associated with and symbolic of curing
pathological illness (even if this is not the direct purpose of the treatments being given, nor a treatment of the ‘main’ life limiting illness such as cancer or heart failure) start to become valid alongside palliative and supportive measures.

When these competing ways of addressing patients needs (palliative and curative) come to be applied to a single subject there may be an irresolvable quality to the decision making around treatments where a patient may be considered symbolically both ‘palliative’ and ‘curative’. Philosophically both courses of action have become justifiable and can validly be called ‘palliative and supportive care’. However, both courses of action (curative and non-curative) are unable to operate equally. Foucault, in his work on the history of medicine, is clear that power/knowledge associated with pathological medical discourses permeate modern healthcare focussing on disease processes which require curative agents (Foucault 1973). Alternative forms of understanding and treating illness and infirmity are rendered invalid in relation to the power that these discourses possess.

When operating within modern medicine’s field of power/knowledge palliative and supportive interventions are at times justified in terms of pathological discourses. For example, treatments such as acupuncture and massage have a history in providing comfort and holistic treatment rather than producing traceable cause and effects in relation to specific pathological symptoms (Beal 2000). However, ‘comfort’ is not a concept which is viable within a pathological field of power/knowledge resulting in treatments such as acupuncture using pathological and statistical discourses such as reductions in nausea (Molassiotis et al. 2007) to justify their implementation. Therefore, exactly what palliative and supportive care is may be being rewritten by medical discourses focussing on treating pathologies rather than providing non-pathologically and statistically justifiable measures.

Palliative care may therefore cease to become a philosophy that rejects one set of measures (curative treatments) in favour of purely non-curative treatments, and instead may be becoming rewritten by the power/knowledge of pathological medical discourses to treat pathologies rather than focussing
on providing comfort outside of a pathological model. This is not to say that treatments of pathologies cannot provide comfort, merely that models of palliative and supportive care that argue for a blurring of pathological and palliative models of care (Zimmermann and Wennberg 2006) have failed to account for how prevailing power/knowledge fields may operate to legitimate one discursive framework over another. Therefore, instead of a ‘blurring’ occurring there may be a rewriting of palliative and supportive care which delegitimises discourses such as ‘comfort’ and non-curative treatments, only making valid treatments which can adopt some form of pathological discourse. This is not making judgement about the way that palliative and support care has colonised and become colonised, nor should it be read as medical staff having power; instead it is a comment on how power/knowledge performed by subjects produces, maintains and furthers pathological discourses over non-pathological discourses (Foucault 1973) and how they in turn may rewrite palliative and supportive care. This rewriting makes palliative and supportive care problematic to define, but it is this very undefinability that makes quality palliative and supportive care potentially re-definable with different discourses once pathological discourses have been accounted for as the prevailing field of power/knowledge.

1.3.2 District nursing

The term ‘district nurse’ has its origins in Liverpool in the 1860s (Buhler-Wilkerson 2003) and was applied to nurses with a specific set of training and qualifications. However, the requirement to achieve a particular qualification before one could use the term district nurse is no longer standard practice with neophyte nurses assuming the title district nurse (QNI 2011).

It is not just the use of title that has changed: the tasks that district nurses undertake have also developed. Until the 1990 community care act (Great Britain 1990) it was common place for district nurses to be involved in the washing and dressing of patients in the community. However, post-1990 healthcare and social care was split with ‘personal care’ (such as washing and dressing) being delegated to local authorities and staff who may have no formal nursing qualifications, and ‘nursing care’ (such as dressings and
medicine administration) remaining within the domain of ‘district nursing’. More recently work by the Queens Nursing Institute (QNI) suggests that this delegation of tasks has continued to progress with more technical tasks such as catheterisation and dressings being delegated to nursing auxiliaries (QNI 2011).

Therefore, the term ‘district nurse’, in a similar way to palliative and supportive care is unstable, has changed and developed and continues to do so. Whilst organisations like the QNI make value judgements about the use of the term ‘district nurse’ suggesting that it is somehow special and reserved, such judgements are not made here. Instead, this discussion merely aims to demonstrate the pliability and problematic nature of the term ‘district nurse’ so that it may be further critiqued in this thesis.

However, because of this complexity and variation that is ‘district nursing’, for the purposes of recruitment for this thesis, the term ‘district nurse’ is left open for registered nurses to either self-identify or be interpellated by their employers.

1.3.3 Patients and carers

The terms ‘patients’ and ‘carers’ have received very little critique in palliative and supportive care literature. Whilst the term ‘client’ is used by Oudshoorn et al (2007b), notably in a study examining power relations, the term ‘patient’ appears to be the generally accepted term in the literature. However, this is not the case for other areas of health and social care research where the term ‘patient’ has been criticised and compared to other possible interpellations such as service user, consumer, and client (McGuire-Snieckus et al. 2003; Simmons et al. 2010). The changing of terms has often been an attempt to move away from the power relations that existed between the professional and the object of the professional’s concern with successive re-interpellations (McLaughlin 2009). That ‘patient’ has almost exclusively been used in healthcare (including palliative and supportive care) literature may be significant and perpetuates a particular way of being an individual who receives palliative and supportive care in a relationship with a professional.
Likewise, the term ‘carer’ cannot be easily defined. Twigg and Atkin (1994) have suggested four sub-types of carers: carers are resources, carers as co-workers, carers as co-clients and the superseded carer (those relinquishing the role of carer). However Payne and Ellis-Hill (2001) highlight that ‘carers’ may not identify as carers at all. Instead conceptualising their relationship with the patient as a wife, husband, son, daughter, neighbour etc. understanding their ‘caring’ as part of that relationship and identity, rather than needing to create a new identity for themselves called ‘carer’.

The term ‘carer’ itself has also been explored through a Foucauldian genealogy to demonstrate how the discourse of ‘carers’ has come to be an effective way of extending the influence of medical discourses through family and friends to regulate and produce the self-regulation of patients (Heaton 1999). Therefore, the literature suggests that the term ‘carer’ is a complex and multifaceted discourse with no clear definition.

For the purposes of recruitment, patients are considered individuals who receive care from a healthcare professional (in this case district nurses); and carers individuals who provide additional support which does not form part of their main employment, though limited financial recompense may occur in some cases. However, for the rest of the thesis the lack of any one single satisfactory definition of patients and carers is used as a tool for analysis and discussion.

1.3.4 Quality care

The term ‘quality care’ is possibly the most elusive of all the key terms used in this thesis and whilst some attempt at exploration is given here, this is mainly to demonstrate the contradictions present and the need for further research. Chapter two and chapter three offer a more detailed history and critique of ‘quality care’.

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1 Through the thesis, the term ‘carer’ is used to denote lay carers, i.e. those who are not caring for professional employment. However, it is possible there is some financial recompense i.e. carers allowance. Other carers are referred to as their professional name i.e. nurses, social services, medical staff etc.
However, briefly ‘quality of healthcare’ has been a longstanding discussion within healthcare literature, with a wide array of ways in which it has been conceptualised such as: compliance with ‘best practice’ guidelines (Donabedian 1966); improving patients’ and carers’ satisfaction rates (Singer et al. 1999); fiscal efficiency (Wiener 2000); and achieving ethical care (Huycke 2000). As with the other terms presented in this thesis, the indefinability of quality of care will be used as a way to produce an analysis which challenges many of the current assumptions in the research literature.

1.4 Healthcare policy and philosophy: an overview

Whilst deconstructing the above terms will be productive later on in the thesis for analytical purposes, a brief discussion of national, and palliative and supportive care policies is presented below to give context to data collection and findings.

1.4.1 National healthcare policy

Neoliberalism has been a significant political force since the 1970s, becoming an increasingly pervasive ideology across the traditional political divide. It aims to use free market forces rather than the state to produce efficiency and quality in a wide range of services from transport and utility provision to healthcare (Timmins 2001). Healthcare policies in developed nations have followed in line with neoliberal reforms in countries such as Canada, USA, Australia (McGregor 2001) and even the more social democratic Scandanavian countries (Saltman and von Otter 1987). In the UK the neoliberalisation of healthcare began with the Thatcher government introducing general management and internal markets (DHSS 1983). It was argued that being able to choose within a market would increase efficiency and quality of care, and reduce the power of hospital consultants (Holliday 1995). Since its inception governments have used neoliberalist ideas of market forces in a variety of ways. The Conservative governments, Thatcher/Major [1979 to 1997] and the current coalition, utilised GP commissioning, arguing that GPs are ‘closer’ to patients and can therefore operate a more patient centred market. The Labour
Governments Blair/Brown [1997 – 2010] on the other hand championed a 'patient led NHS' with a strong rhetoric of direct patient involvement:

“You [patients] have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.” (Department of Health 2009b: 3)

For Labour, choice became something which individual patients rather than GPs could exercise to produce quality not only for the individual but also within entire services and the NHS in general (Darzi 2009). This patient involvement was however, generally considered to be weak and more rhetoric than reality (Nordgren 2010) with management and non-patient led targets such as the Gold Standards Framework (Dale et al. 2009) featuring strongly in healthcare policy and practice. Therefore, whilst neoliberal notions have been operated in different ways, recent political history has continued to tie the idea of individual (consumer) choice with healthcare marketisation in order to produce quality whilst at the same time increasing efficiency.

1.4.2 Palliative and supportive care policy

Whilst highlighted as a problematic term above, as a distinct philosophy of care palliative care began with Cicely Saunders working to establish the first modern hospice, St Christopher’s in 1967 (Clark 2007). The focus was primarily on caring for the dying, something which as discussed above modern palliative care has aimed to broaden. In the UK a political drive to increase palliative care in the UK earlier on in the disease process began in the mid 1990s with the Calman-Hine report where, in keeping with the World Health Organisation, it was recognised that palliative care had a place earlier on in the disease process (Expert Advisory Group On Cancer 1995). However, this policy document only pertained to cancer, whilst there was recognition in the academic literature that many non-cancer patients had palliative care needs (McCarthy et al. 1996), government policy in this area was lacking.
The National Institute of Clinical Excellence (2004) report continued the focus on palliative and supportive care in cancer, but highlighted that many of the suggestions for improving palliative care could equally be applied to non-cancer patients. Only in 2008 did Government policy begin to focus on providing palliative care to all adults at the end of life, regardless of diagnosis (Department of Health 2008). The success of this policy over the past four years is still being assessed, though figures suggest that specialist palliative care services are beginning to provide more care to those with non-cancer diagnoses; up from 5% in 2000 to 17% in 2011 (The National Council for Palliative Care 2012).

However, palliative and supportive care is not only given by specialist practitioners. When considering palliative and supportive care within the context of community healthcare, district nurses are the largest group of professionals (Department Of Health 2004; QNI 2011) and key providers of such care (Seale 1992; Beaver et al. 2000; Appelin et al. 2005). The National Council for Palliative Care Report (2012) does not represent the work that this large group of healthcare professionals does, and the ways in which district nurses and other 'non-specialist' community healthcare staff such as GPs offer palliative care to different demographic groups. Research in this area suggests that generalist healthcare professionals are still biased towards providing palliative care to cancer patients (Shipman et al. 2008) and that for non-cancer patients there remain unmet needs (Currow et al. 2008). However, other research suggests that this 'unmet need' is in fact being met (at least for some heart failure patients) away from generalist services such as in heart failure clinics (O'Leary et al. 2009).

In an effort to bring the ‘good practice’ in specialist palliative care (which has often been cancer centric) over to a generalist and non-cancer setting several tools have been developed, three of which have been promoted on a national scale, namely: the Liverpool care pathway for the dying (Ellershaw et al. 2003), gold standards framework (GSF) (King et al. 2005), and preferred place of care (Storey 2007).
The Liverpool care pathway is inspired by hospice practices which aim to facilitate high quality standardised care in the last hours and days of a patient’s life (Ellershaw et al. 2001). Whilst this is a laudable aim, it is questionable whether the ‘excellence’ of hospice care can be reduced down to a set number of procedural steps. There may be cultural differences in hospices which alter the experience of patients and their carers (Froggatt 1997; Lawton 2000) and little is known about how these characteristics of hospice care contribute to the perceived excellence in caring for the dying.

Research suggests that the symptoms experienced by dying patients are broadly similar regardless of diagnosis (Solano et al. 2006) and it has been suggested that the Liverpool care pathway can help improve the symptoms of patients at the end-of-life (Veerbeek et al. 2008). However, instigating the Liverpool care pathway by ‘diagnosing dying’ is complicated by the differing dying trajectories observed for different diagnostic groups such as cancer, organ failure and dementia (Lynn and Adamson 2003; Murray et al. 2005; Gott et al. 2007). This is not to say that symptoms cannot be treated without being commenced on the Liverpool care pathway, but it does question that quality of care can be achieved by instigating the procedural steps in a care pathway developed in a hospice cancer-centric environment (Ellershaw et al. 2001; Help The Hospices 2010) which may not be representative of other disease groups and social contexts. Instead, it may merely be a case of instigating care that should occur regardless of the paperwork that is used to support it. However, despite these limitations with the evidence around the Liverpool care pathway it has been recognised and promoted by influential policies (Department of Health 2006; National Institute for Clinical Excellence 2004).

The GSF was developed via the MacMillan GP facilitator programme. Broadly speaking it is a collection of medical processes which are considered to enhance palliative care (Thomas 2003). Whilst this is not in itself problematic, using medical discourse to establish quality in palliative care does have consequences. Many of the aspects in the GSF are process driven goals tied to financial incentives. For example, points (and money) are awarded through the quality outcomes framework in palliative care for establishing supportive care registers and conducting MDT meetings. This clearly places emphasis on
institutional quality and financial incentive rather than the patient experiences of care. In addition, whilst potentially enhancing patient care, the GSF also creates a lot of additional work potentially reducing time for other tasks (Munday et al. 2007). The evaluations which have been carried out have generally examined the extent to which the GSF has been implemented, not whether there has been an increase in the quality of palliative care, the aim of the GSF. These evaluations have also been carried out by the team which is instigating the GSF (Shaw et al. 2010) possibly biasing results. Walshe (2008) did independently examine the GSF, and concluded that healthcare professionals were generally positive about its implementation and felt that the level one aims and protocols for out-of-hours services and prescribing were particularly welcome. However, Walshe also noted that there was often a liberal interpretation of when certain goals had been established. Research is lacking on its effectiveness at improving the quality of care from a patients and carers perspective (Shaw et al. 2010).

The process of recording and achieving a patient’s preferred place of care is considered by government policy to be a mark of quality in palliative and supportive care (Department of Health 2009a). The main document being promoted as facilitating discussions around preferred places of care and death is the *Preferred Priorities of Care* document. However, it has been suggested that term ‘care’ may at times be used by healthcare professionals as a euphemism for death and that the terms are not synonymous (Agar et al. 2008; Grande and Ewing 2009). Despite this semantic problem, Grande and Ewing (2009) question the importance of place of care/death, suggesting that it is the general circumstances surrounding the patient’s death rather than the place of death *per se*.

Therefore, all three of these documents have wide scale influence in the provision and organisation of palliative and supportive care but further research is required to evaluate them in reference to patients’ perspectives.
1.4.3 Community palliative and supportive care: policy and choice

There is an increasing focus on providing palliative and supportive care in the home (National Institute for Clinical Excellence 2004; Department of Health 2008). This is justified in a variety of ways, that home care: is cheaper than hospital care (Jones et al. 1999; Serra-Prat et al. 2001); produces higher satisfaction rates (Brumley et al. 2007); and, increases patient choice (Austin et al. 2000; Griggs 2010). However, these justifications have limitations. The argument that home care is cheaper than hospital care has been questioned by a 2005 Cochrane review which suggests that the costs for hospital and home care are equivalent (Shepperd and Illiffe 2005). Satisfaction rates and increasing choice are also problematic because there is little known about what it is that patients understand to increase satisfaction rates with home care, therefore it cannot be understood why patients and carers may be choosing home care. For example, whilst research has investigated the factors that affect the statistical likelihood of patients achieving their preferred place of death (Bell et al. 2010). Most of these factors (such as being married) are fixed and unable to be altered, and for most patients no choice exists with who provides their home nursing care. This all questions whether choice truly operates in community palliative and supportive care. Hence, it is not only important in this thesis to consider what contributes to quality of current palliative and supportive care in the community; but also how policy and practice may develop to facilitate the neoliberalist notions of patient and carers making choices about their care.

Therefore, researching patients’ and carers’ views of palliative and supportive district nursing care within a post structuralist framework is an important and timely topic. Such a framework promises to challenge the ways in which power/knowledge and the subsequent circulation of discourses may privilege certain ways of conceptualising quality care.
1.5 Layout of the thesis

Following the introduction to the study, chapter two lays out the theoretical framework that is used to rework an understanding of quality of care at an abstract level.

Chapter three is the literature review. It was conducted prior to data collection for two main reasons. Firstly, it was felt that taking time away from participants if similar research had already been done would be ethically questionable. Secondly, it allowed the current hegemonies within this particular academic field to be examined and therefore open to direct challenge within the interviews with participants.

Chapter four discusses and critiques the various methodological approaches that may be used in qualitative research in relation to the principles of post-structuralism. Chapter five gives a detailed account of how the study was conducted. It highlights how at times the approaches espoused in chapter four did not work as expected and documents how these difficulties were overcome. It also gives a detailed account of how analysis was conducted and a summary of the socio-demographic findings.

Chapters six, seven and eight provide an account of the key study findings in relation to the theoretical framework. The three findings chapters do not discuss the findings in relation to wider literature, this is reserved for chapter nine.

Chapter nine discusses each of the findings chapters in turn, examining how each of the findings work together on a moral level addressing what this might mean for district nursing care at a policy level and an individual nursing level.
Chapter 2

Theoretical positioning

2.1 Philosophical positioning

This chapter explores post-structuralism as the guiding philosophy for the way in which this thesis is conceptualised. The first half of this chapter discusses post-structuralism and justifies its use in the thesis drawing from Foucault, Deleuze and Butler, explicating and critiquing it in relation to other possible philosophical approaches. The second half builds upon this critique, focussing specifically on post-structuralist approaches to morality and quality of care, opening up new analytical and subjective possibilities, particularly focussing on patients and carers. Chapter four discusses how post-structuralism intersects with the methodological aspects of this thesis such as data collection, analysis and writing.

2.1.1 Reforming power

One of post-structuralisms key contributions to research has been its reworking of the concept of power. Post-structuralism moves away from modernist views of power, which understand it as something that can be possessed by individuals, towards an understanding of power which circulates forming and reforming\(^2\) subjects (Foucault and Gordon 1980; Butler 1997b; Cheek 2000; Belsey 2002). To be clear, ‘subjects’, is not merely another word for individuals. It is instead a concept which encapsulates the discursive position that is carved out in language that individuals will then go onto occupy but not possess\(^3\) (Butler 1997b).

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\(^2\) Within this thesis for the sake of brevity and in keeping with academic practice when discussing Butlerian concepts forming and reforming will be expressed by the use brackets around the ‘re’ thus: (re)form.

\(^3\) Hence throughout the thesis when talking of patients and carers subjectivities, there is no possessive apostrophe.
In researching patients’ and carers’ views, searching for power in the caring relationships helps reveal aspects of the data that other approaches such as positivism and constructivism are unable to account in such detail for how these positions arise. Positivism, for example, views reality as external and pre-existing to the individual (Edwards 2001). By taking this stance subjects are treated as unproblematic and researchers are understood as being external to the research being addressed. In doing this, the workings of power cannot be revealed because individuals and reality are understood to exist regardless of any external influences allowing social situations to be read and understood as they are directly presented.

Constructivism, does not assume reality is external and pre-existent and instead views reality as a construction between subjects (Charmaz 2006). It therefore has some space to allow for how power may influence one construction of reality over another by virtue of allowing for multiple realities shaped by subjects. However, power remains untheorised in constructivist thinking as a way of forming the subject, Instead it is only considered in instrumental terms: “relative differences in power may be acted on and played out during the interview. Powerful people may take charge...” (Charmaz 2006: 27). Power is therefore understood as something which individuals can possess and use rather than something that forms subjects. Within constructivist philosophies no account is given about the subjectivity of the one doing the constructing (Butler 1993). Power in the post-structuralist thinking of Foucault, further developed by Butler attempts to account for how the subject is able to ‘construct’ and are themselves ‘constructed’ (Foucault 1977; Butler 1993, 1997b). Using power to analyse this process theorises both the subject doing the constructing and the limits to their accounts opening up new analytical possibilities.

2.1.2 Power/knowledge: a post-structuralist understanding

Foucauldian power is linked to the production of knowledge and knowledge is linked to the production of power. Foucault sees little distinction between the two forming in his later years the concept of power/knowledge:
“Knowledge linked to power, not only assumes the authority of 'the truth' but has the power to make itself true. All knowledge, once applied in the real world, has effects, and in that sense at least, 'becomes true.' Knowledge, once used to regulate the conduct of others, entails constraint, regulation and the disciplining of practice. Thus, there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time, power relations” (Foucault 1977: 27)

Power, when conceptualised this way, is neither positive nor negative, instead it is productive, producing practices and positions of subjectivity; sanctioned ways of being, or to use a Foucauldian term “regimes of truth” (Foucault and Gordon 1980: 131). However, in Foucault’s work power is mainly theorised through institutions such as hospitals (Foucault 1973) and prisons (Foucault 1977) controlling the subjective positions through the sanctioning of knowledge. For example, in hospitals subjects are lined up in beds and categorised into a variety of illnesses through recourse to medical knowledge. The system gains its power from this medical knowledge to work the bodies of the patients submitting to various investigations and treatments (Foucault 1973).

Whilst in his later works and lectures he begins to theorise how power permeates society to the smallest details, it is not always clear theoretically how it occurs outside of an institutional setting other than though a rather unspecified and under theorised trickling down effect from institutions to individual lives (Foucault 1977; Foucault and Gordon 1980). Therefore Foucault’s understanding of power whilst usefully refuting the idea that individuals possess power, remains theoretically tied to institutions and only shapes rather than forms the subjects. Whilst it remains a valuable understanding, if wishing to examine how power functions in individual lives and relationships outside of institutional settings, such as the home, a turn to a Butlerian understanding of power is required.
2.1.3 Power as subject formation

Butler takes Foucault’s ideas of power and intersects them with psychoanalytical theories (Butler 1997b, 2005). By doing this Butler aims to understand how subjects are not only reformed by but are formed through power/knowledge. This is important for the analysis of the district nurse-patient-carer relationship because the patient and carer subject can be understood as being formed in the home in direct relation to the district nurse. Whilst individuals with medical needs are likely to have been patients before either in hospital or at GP surgeries, they would not fully remain so in the home. In this thesis developing a more detailed understanding of how power/knowledge operates away from institutions will help theorise what quality of care may look like in the home.

For Butler, unlike Foucault, power forms the initial viability of the subject, without being subjected to power, subjects are unable to enter into the social world and in doing so take on a viable identity becoming a viable being (Butler 1997b). However, because this subjection pre-exists the subjects existence, subjects are unable to account for how power forms them. In her earlier work gender is used to demonstrate how to become viable one must submit to the discourse of a binary gender when born with the declaration “it’s a girl” or “it’s a boy” (Butler 1990). If there is ambiguity in the genitalia, in order to make a viable subject, medical discourse aims to ‘correct’ the child, making them either viably male or female. This however, is not the only task to be achieved in being gendered, instead gendering is a continual process which must be performed and re-performed in line with extant discourses, a process Butler describes as performative (Butler 1990, 1993).

Moving away from gender as her central concern and broadening her horizons to being and existence in general Butler recognises that:

“[subjects] pursue subordination as the promise of existence… [yet] becoming is no simple or continuous affair but an uneasy practice of repetition and its risks, compelled yet incomplete, wavering on the horizon of social being.” (Butler 1997b: 30)
Patients’ and carers’ identities can therefore be understood as: formed in a subjection that is unaccountable for by patients and carers yet essential to their existence; and, continually required to reform and maintain their existence, unable to escape that which made them viable. This original formative function of power/knowledge produces subjects who submit to extant discourses in order to exist and must continue to do this to remain viable existing subjects. This forms subjects who are inextricably linked to the social (which they submitted to) and ‘the Other’ who enacted the discourses that they submitted to. The Other is a complex and long debated psychoanalytic concept, the details of which go beyond the relevance of this thesis. However, in brief, the Other conceptualises the process through which a newborn baby comes to recognise itself as individual. Psychoanalytic theory posits that initially a newborn child has no sense of self, it gains this sense of self through recognising that there are Others which it is not. In this way, a psychic and social separation occurs which is reliant on the child recognising that there is the Other and indeed that the self is an Other to others (Bailly 2009). For Butler this means that individuals cease to be truly individual but instead have subjectivities that are reliant on other subjects to be. This could appear to suggest that Butlers interpretation of post-structuralism is deterministic with no opportunity to live one’s own life in the ways one chooses, instead always having to be in deference to the Other which one has no control over. This would be a misunderstanding. Instead Butler is trying to demonstrate that one must first become a viable subject who acts in the social world via extant discourses which the subject has no control over. Once viability has been achieved one can begin to question and challenge, exceeding but not escaping ones subjectivity in multiple ways through repeating discourses in different or even erroneous ways (Butler 1990, 1993, 1997b). It is this very requirement to repeat discourses constantly which suggests that they are in fact unstable and therefore changeable (McNay 1999).

4 The Other, in keeping with standard practice, is given a capital ‘O’ to denote it from the colloquial use of the word.
2.1.4 The necessity of the Other but the rejection of the material

What remains unclear with such an explanation of psychic-social (re)formation is how and if material circumstances come to (re)form subjective experience in addition to or in contradiction to the Other. Without wanting to be facetious, within Butler’s theories one could largely imagine disembodied voices alone doing the work of power/knowledge. Whilst Butler approaches the material in some of her works (Butler 1997a, 2004) it only tends to be in relation to the fact that bodies can be physically injured which produces a primary vulnerability to the Other. However, there remains no coherent discussion or explanation of how material conditions effect subjectivity, such as those observed in aspects of Foucault's work (Foucault 1977). Therefore, developing a theory of how the material and the discursive interact is an important consideration in this thesis but does not detract from the utility of Butler’s theories to open up a novel debate on the morality of actions.

2.1.5 Relation to this thesis

Butler’s work on morality can be applied to this thesis by not examining the ‘construction’ of quality district nursing by the patient and carer but instead asking what discourses are used to allow patients and carer to become and be viable subjects and how this might restrict their being and subsequent thoughts on district nursing care. Theorising within a post-structuralist framework also helps understand how discursively produced subjective positions are not truly individual, but entirely reliant and co-constitutive. Examining how these identities form each other offers novel analytical possibilities to the quality of care literature which fails to account for how the formation of subjectivities is intrinsically linked to the performance of what quality of care is and can be and how power/knowledge restricts and (re)forms possibilities.

Theorising post-structuralist morality in the next section will introduce a new way to understand quality care which understands (re)forming subjectivities as a moral action and hence quality care.
2.2 Theorising a post-structuralist quality care

To critique and develop a post-structuralist philosophy towards quality care, two sets of questions can be asked: firstly, what is a moral action and how can one be recognised; secondly, within healthcare to what extent can moral or immoral actions be said to be indicative of quality of care being given? Answering these two questions on a broad philosophical level opens up morality as a framework for quality of care to be critically debated with particular reference to palliative and supportive care scenarios.

2.2.1 What is a moral action and how can one be recognised?

In beginning to think about moral actions it is important to highlight that moral and immoral actions are not merely restricted to what might be best referred to as ‘dilemmas’; for example debates around euthanasia or refusal of treatment. Whilst these are important debates, it is important to recognise the rarity of such events and that if such events are rare, it becomes questionable how applicable they are to everyday nursing. Therefore, the aim of this section is reconceptualising morality in nursing as an everyday process, to allow for everyday actions to be examined which may have previously been taken for granted as ‘just being nursing’ and instead highlighted as key points in analysis.

Deleuze and Guattari (1988) suggest that moral actions lie in allowing subjects to become-other by resisting the totalising and restricting effects of power and applying new discourses to one’s being. One way in which this could be conceived of in an abstract way is to allow subjects to reply to the interpellation of power with ‘I am not that, I am this’. Yet the ‘this’ within a Butlerian framework must remain as an extant discourse that is viable and sanctioned as such within the broader social world requiring constant repetition to maintain it. This restricted form of performative repetition allows subjects to gain insight into the power which forms and restricts them whilst not fully removing those structures, making them unviable; a balance which allows subjects to be simultaneously viable yet resist the totalising and restricting
effects of power that forms them. If therefore, moral action is to be achieved, that of allowing subjects to change and develop, responsibility for this must also lie in those who address subjects, the speakers, who must account for how they allow subjects to reply with ‘I am not that, I am this’.

Firstly one must question the completeness in knowing the other subject with: ‘Do I know you’. This allows for the other and the speaker to reply ‘No’ which crucially allows for a second step questioning how the speaker and subject know their own being: ‘how do I, and you, know you’. The ‘how do I know you’ part of this statement pushes for the speaker to realise the language and discourses which they are using to make intelligible the one they address. The ‘how do you know you’ allows for the person being addressed to critically reflect on the language and discourse that they come to understand themselves within and allow them the opportunity to reform themselves opening up the possibility of change. Putting these two elements together gives a new abstract phrase for considering the nature of moral actions: ‘Do I know you, and if so how do I, and you, know you’.

It is important to interrogate the extent to which this reformation can take. This is because as mentioned earlier subjects have to remain viable subjects (or risk ceasing to exist) and therefore subjects and the others that they address must remain within some form of intelligible discourse which is mediated through language. There is therefore no entirely moral act or way of being even if we always act to try and allow constant becoming-other because the act of addressing a subject in language is by such a measure itself immoral by bringing the subject into being through a finite language fixing their being within this language which they must respond within to remain viable. Therefore, immediately restricting their becoming-other and curtailing their ability to resist the totalising effects of power.

Instead, morality is limited to allowing the possibility of subjugation to exceed its genesis. Accepting this intrinsic limitation to moral action it is now time to examine the implications of this understanding of morality within a healthcare setting.
2.2.2 Is a moral action indicative of quality care?

What then can post-structuralist morality contribute to the analysis of quality care? It certainly cannot lead to any quantifiable figure, nor is it likely to lead to the establishment of procedures that can be followed, nor is it going to be able to explore the outcomes of biomedical care. Instead, as already alluded to, it can help ground the discussion in day to day actions which form subjects and examine for ways in which these subjectivities are either restricted or emancipated. Therefore, the question in healthcare seems to be, to what extent can nurses practice the moral way of acting ‘Do I know you, and if so how do I, and you, know you’?

2.2.3 Theorising moral practice in palliative and supportive care

If we accept that subjects are formed by power/knowledge bringing them into viable but primarily subjugated subjectivities, including being patients and carers. What space is there to critique quality in palliative and supportive care in terms of a post-structuralist morality?

The recent NICE guidelines on quality in palliative and supportive care provide a useful starting point to rethink quality care in terms of morality. The quality markers appear to roughly follow a typical patient’s journey, starting with being identified as a palliative care patient:

“People approaching the end of life [one year prior to death] are identified in a timely way” (NICE 2011: 9)

treatment through illness:

“People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.” (NICE 2011: 9)

to death and bereavement care:
“People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.” (NICE 2011: 9)

By reading this in a post-structuralist way, immediately one is drawn to question who is identifying, what knowledge allows that identification to occur, and what effects this has on the way that subjectivities are allowed to develop. Increasing research leading to increasing knowledge in palliative care practice will within a post-structuralist understanding also lead to an increasing power to produce and control the objects of the discourse, patients and carers. If this body of knowledge is as holistically focussed as it claims to be and aims to address all of the patients and carers needs then increasingly subjectivities will be further formed by the power derived from this ‘holistic’ power/knowledge. This may then subsequently lead to all aspects of palliative and supportive care being delimited, disallowing patients and carers the possibilities of novel subjective positions.

Therefore for moral care to occur, when posing ‘do I know you, and if do, how do I and you know you’, there must be space within a palliative care discourse to answer no and to allow subjectivities to be exceeded; holistic knowledge cannot be allowed to become total power/knowledge. Knowledge which is not within palliative and supportive care discourses must be allowed to reform the patients and carers subjectivities for care to be considered moral. Equally, nurses should aim to bring in ways of being which are not related to palliative and supportive care. This is not to say that palliative and supportive power/knowledge is negative, it is productive of subjects and in many cases may prove extremely effective in relieving distress and discomfort. However, if increasing knowledge results in all acts by patients to be immediately inscribable and knowable through palliative care discourses, always answering ‘yes’ to ‘Do I know you’, subjectivities will never be afforded the opportunity to exceed and care will become immoral.
Therefore, if: supportive and palliative care research and subsequent practice builds a body of knowledge to delimit ‘best practice’; focuses on, what must or should be done to achieve quality care; and is, followed without accounting for and taking action to assure the moral consequences of this knowledge. Palliative and supportive care research and practice will produce an immoral form of care by power/knowledge increasingly restricting patients and carers subjectivities.

2.2.4 The limits of post-structural morality in palliative and supportive care

However, is this idea of nurses encouraging this exceeding of patients and carers subjectivities always possible? Is it possible that this exceeding could in fact in the short to mid-term be quite disconcerting for patients whilst they search for a new discourse to understand themselves in? Immediately this seems to be tied up with paternalistic ideas that totalise the patient saying ‘I know what is good for you’ rather than letting patients inscribe their own being within the discourses that they may choose from, and so must be rejected as a solution. How then should morality be decided in scenarios where patients/subjects have a severely curtailed time to live and/or energy to invest?

For the dying and severely ill patient, it may be immoral for the nurse to start a process which cannot be completed. Therefore, in situations where patients may lose their ability to become and change the moral response to the question ‘Do I know you’ could the answer be ‘yes’ but be coupled with a critical reflection and realisation of the regimes of truth that the nurse and patient are working under and whilst not producing its change, instead opens up the possibility of becoming-other. It therefore appears that nurses (and indeed all healthcare professionals) are required to always ask the questions ‘Do I know you’ of all subjects/patients that they encounter and recognise the regimes of truth that they are working under. What is not required therefore is change in itself, but the possibility of change.
This scenario however raises the question of how we can establish responsibility for the initial actions that produce the possibility of becoming-other in a subject. If *subjects* come into being through the initial act of subjection to power, by its restricting (yet necessarily so) nature this cannot be considered moral. Instead both parties, the nurse and the patient, are dually responsible for reacting rather than acting in a moral way to each other’s actions. Therefore, the statement ‘Do I know you, and how do I and you, know you’ is not a universal way of morally acting, but may be better understood as a moral way of reacting. In being recast in such a way it removes the imperative for change on either party which creates a dilemma in situations where it may not be achievable. Therefore reactions rather than actions can be considered moral or immoral. Moral nursing practice can therefore be examined for where reactions to patients and cars open up the possibility of exceeding the limits that form their being by opening up the possibility for novel discourses to reform patients’ and carers’ *subjectivities*.

Examining practice within this framework, looking for care which allows a reaction to and produces an exceeding of the discourses that originally brought the patient and carer into being will therefore form the analytical framework for this thesis.
Chapter 3

Literature review

3.1 Introduction

Whilst some research methods would encourage reserving the literature review until after data collection (Glaser and Strauss 1968; Glaser 1998); to do so risks the researcher being unaware of the hegemonies present in their field precluding any direct critique of them via empirical research. Therefore, this literature review serves as a starting point for understanding what hegemonies are present in the topic area. In this way the empirical research can be directed to challenging rather than reproducing these hegemonies.

Initially an overview of the quality of care literature is provided in order to understand how the field is structured. Then the focus moves to the literature on district nursing palliative and supportive care. Following this a systematic review is undertaken on the current literature of patients’ and carers’ views of palliative and supportive district nursing care.

The aim of this section is not to provide and conclude on any form of definition of quality of care; this would begin to close down analytical possibilities and prevent the deconstruction of the topic. Instead, the hegemonies are going to opened up and challenged throughout this thesis. This will be achieved by deferring any form of definition and instead allowing the tensions and contradictions in the quality of care literature to enter into a relationship with empirical data gathered in this project with conclusions regarding any firmer definition of quality of care being addressed in chapter nine.
3.2 Quality of care

There are various ways in which quality of care has been conceptualised, but two key distinctions can be made in all cases. Firstly, temporal effects i.e. whether to assess single or multiple episodes of care, and secondly whose perspective, if anyone’s, is given precedence in deciding what constitutes quality (Donabedian 1979, Scholle et al. 1996).

3.2.1 Temporal effects on quality of care:

In the field of accident and emergency (A&E) it could be reasonable to conceptualise quality as practitioners’ application of up to date research and how this improved aspects such as mortality rates. In short term admissions, if disease was successfully treated, quality care could be said to have taken place. However, when examining chronic and palliative care a longitudinal (i.e. more than one distinct episode of care for the same problem) picture is needed because the care itself is often longitudinal. Concepts such as relationship building and continuity are consistently reported as important factors that affect quality of palliative and supportive care (Higginson et al. 1990; Grbich et al. 2001). However, suggesting that there is a dichotomy of settings, some requiring the assessment of single episodes of care and the other multiple, is an over simplification. For example, older patients and those with palliative care needs can repeatedly present to accident and emergency and not have their needs met (Bentley and Meyer 2004; Perreault et al. 2004). Therefore, to dichotomise the assessment of quality to single/multiple episodes depending on the setting may result in silencing the needs of patients and carers who require continuity and relationship building.

This is not to say that no continuity can take place in settings such as accident and emergency; for example it is possible that case notes from previous admissions are accessed. Instead, the point being made is that silencing aspects of quality depending on the setting could result in service provision measuring quality in ways that may not be relevant to, and/or omitting relevant
measures (such as relationship building) that effect patients accessing the service. For example, the target: “no one will spend longer than four hours in A&E before being discharged or admitted to hospital, unless clinically appropriate…” (Department of Health 2005a) is problematic because the phrase “clinically appropriate” could be interpreted as, but is not limited to, medical needs. It is possible patients and carers with palliative and supportive care needs would value relationship building but this is precluded as a measure of quality and is therefore not a valid reason for deviation from the four hour target. Temporality in this way forms what quality care is allowed to be possibly silencing the needs of patients and carers.

3.2.2 Perspectives and their effect on defining quality of care:

Donabedian (1980) suggests four possible perspectives on quality in healthcare: professionals (nurses, doctors etc.), managers (healthcare and generic), service users (patients and carers), and the funders (taxpayers/community who are paying in state funded systems, employers, insurers and individuals).

*Healthcare professionals’ perspectives:*

The perspective of the medical professional is often limited to medico-scientific conceptualisations of quality care; whilst nursing pushes to account for ‘emotional work’, it is often not represented because of the dominant medico-scientific framework (Bone 2002). The inclusion of patients’ and carers’ views in assessing quality of care has been dismissed in the past as being overly complex (Donabedian 1980) and that ‘quality of care’ should be defined as the extent to which care is in conformity with present medical criteria (Blumenthal and Epstein 1996; Donabedian 1966). This is problematic because clearly medical criteria only represent one side of any healthcare interaction. For example, whilst it is possible to see that measuring patients’ and carers’ views on the quality of the relationship with their healthcare professional is not as straightforward as objective measures such as mortality, it does not mean that
it is less valid, merely that more research is needed to facilitate ways of incorporating patients’ and carers’ views. Arguably some of this work has been done since Donabedian’s commentary (Hearn and Higginson 1997; Aspinal et al. 2003; Department of Health 2009a). Clearly medical conceptions are not the only framework for healthcare professionals to construct ‘quality of care’ within. They are however often the most dominant, with nursing or lay conceptions being seen as ‘alternative’ rather than ‘complementary’ (Cheek 2000). Donabedian and others therefore, may have simply been influenced by the dominance of a medical framework rather than truly comparing the utility of using a medical framework as the basis for assessing quality care. This results in the conclusion that healthcare professionals’ constructions of quality of care are bound within a medico-scientific framework which cannot fully represent the work undertaken in healthcare interactions. This way of conceptualising quality in palliative and supportive care can be seen in hospital rating systems where quality palliative and supportive care is limited to the prescription of opiates and laxatives (University Hospitals Birmingham 2012). Whilst such medications are essential in providing palliative and supportive care, to use them to measure the overall quality of palliative and supportive care, without recognition that there are other elements beyond biomedical/pharmaceutical interventions demonstrates the power with which medical discourses have to define quality of care. Moving beyond these measures is therefore necessary to challenge the increasing dominance of a medical framework in palliative and supportive care.

Healthcare managers’ perspectives:

Healthcare management, particularly in the United States, has received extensive criticism for treating healthcare in the same way as any other industry where cost-effectiveness and efficiency are seen as markers of quality (Wiener 2000). It has been argued that a shift has occurred where cost-effectiveness has encroached upon, and in some cases become a euphemism for, quality of care (Wiener 2000). Within such frameworks, everything has to be given an economic value, but ‘everything’ that patients find in quality care
such as: compassion, friendship, comfort and a pleasant environment (Watson 2009) cannot be represented economically and unquantifiable ideas become de facto outside of economic representation. Whilst it is important that physical healthcare costs such as drug costs are measured and kept in check, the assumption that cost-effectiveness is a proxy or worse a euphemism for quality of care overall is problematic because of the difficulties associated with financially accounting for the non-physical caring aspects of healthcare. At most it forms a small part of a bigger picture.

**Funder views on quality of care:**

The funder perspective has two significant contributors, private funding (either insurance based or individual based) and state funding. It is important to note that palliative and supportive care often receives both state and charitable funding (Help The Hospices 2010) but this is not commented on in research on palliative and supportive care.

The source of funding has considerable effects on the construction of quality of care. For example, private healthcare companies want to ensure that there is a high enough standard of care to retain its customer base, whilst maintaining a profit, and remaining competitive on the open market both from a cost and quality perspective (Wiener 2000). State funded systems on the other hand attempt to balance fiscal limits with providing the most good for the most number of people (Timmins 2001).

Over the past thirty years free market reforms have played an increasing role in balancing costs with quality of care (Timmins 2001; Wiener 2000). However, evidence for its effectiveness as strategy is lacking, and appears to be more political rhetoric rather than justifiable arguments with American healthcare costs (largely based on free market insurance based system) costing the most per capita of GDP in the world (Auerbach and Kellermann 2011). Despite the lack of sound economic arguments for free market healthcare reforms, it is possible to see that adopting a free market approach to healthcare creates consumerism within healthcare which alters the measures used to assess for
quality of care (Irvine 2002). Previously mortality statistics and surgical recovery times may have been used to demonstrate quality of care but due to an increasing consumerist approach to healthcare, a shift has occurred where patients are increasingly given a voice in redefining quality (Darzi 2009).

Patients’ and carers’ views on quality of care:

The UK government has been increasingly advocating patient involvement in healthcare:

“...You [the patients] have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.” (Department of Health 2009b: 3)

In contrast to the views put forward by Donabedian (1966, 1979, 1980) quality is now being measured in more lay or non-biomedical ways. For example, the Care Quality Commission (2008) via the National Patient Survey includes ratings such as “Overall how long did you have to wait to be admitted into hospital”, “Were you disturbed by noise at night from staff?” and “Did you find someone on the hospital staff to talk to about your worries and fears?”. Each hospital is then presented from best to the worst (Care Quality Commission 2008). This survey clearly assesses quality in relation to episodes of care as none of the seventy nine questions investigate previous episodes of care and how they relate to the current episode of care. This is despite one of the final questions being “Do you have any of the following long-standing conditions?” (Care Quality Commission 2008: 26). The surveys utility in assessing quality of care for these “long standing” conditions is therefore questionable when no questions address longitudinal perspectives. Also, recent research indicates
that for out-patient appointments only four percent of patients examined the
data from the national patient survey when choosing a hospital for an out-
patient appointment (Robertson and Dixon 2009), making the extent to which
consumer choice in healthcare affects market forces questionable. The
specificity of the questions are also questionable, whilst the surveys do include
questions on pain management, there is no distinction made between acute
pain management and palliative pain management. In addition there are no
questions that clearly address issues directly relating to patients’ needs at the end of life. Equally, no other national surveys addressing quality of care
appear to produce results which have questions that are specific to palliative
and supportive care. Although there are some surveys which specifically
survey palliative and supportive care populations (iWantGreatCare 2012)
again the questions do not specifically address issues specific to palliative and supportive care. Therefore, consumerism may be particularly problematic
when appropriate information is not present for consumers of palliative and supportive care. Despite this the most recent reforms to the NHS aim to
continue using patient choice in the development and maintenance of quality
care extending the concept of choice to one where patients may access care
from any willing provider (Department of Health 2010b). This it is suggested
will enable individual patients to choose between services thereby compelling
service providers to improve their care in order to remain competitive.
However, this choice remains restricted by there being no legislative
requirement for lay involvement in the GP commissioning process (Great
Britain 2012) further limiting the way in which consumerism may operate.

In general critiques of ‘choice’ as a driving force for quality highlight that
patients cannot be considered as rational consumers in the same way as
consumers of electrical goods can be (Nordgren 2010). However, what has not been considered are the post-structuralist critiques of choice which suggests in order to choose as a patient, one must first become a viable patient by submitting to the power/knowledge of extant discourses; discourse which one has no control over until ones becomes a patient by submitting to a primary subjugation to these discourses. In this way, patient choice will always be intrinsically restricted and its ability to drive healthcare limited because patients
are formed by the healthcare discourses that they are being asked to try to change and develop.

Therefore it is also important to consider the views of ‘non-patients’ (i.e. those not in direct contact with healthcare services), yet still fund healthcare services through taxation. However, the concept of a non-patient is in itself problematic. Firstly, the premise that there are still people in developed countries who don’t have contact with healthcare services is broadly false. With extensive screening and health promotion activities, it is arguable in countries such as the UK that all members of the public come into some form of contact with healthcare services, even if this is just at a discursive level; and when taking a post-structuralist view, discursive contact is not distinguished in any way; all contact is essentially discursive whether materially mediated (i.e. by a nurse entering the house) or not. In this way the patient, non-patient binary begins to break down, and when the definability of patients (and by logical extension carers) is questioned it begins to erode how consumerist approaches function.

If those who ‘consume’ by virtue of their illness are precluded from acting as consumers; and when one is unable to define those who consume; who has the right to speak as a consumer? If we are unable to define those who speak as consumers, then ‘patients-as-consumers’ as a concept to drive quality in healthcare becomes meaningless and a different way of driving and defining quality of care is required which allows for the indefinability of patients and carers.

3.3 District nurses and palliative care

Reviewing some of the contemporary documents about district nursing in relation to quality in palliative and supportive care it appears palliative and supportive care is ‘different’ and that district nurses view it as one of the last remaining areas where ‘holistic nursing’ is practised (King et al. 2004; Appelin et al. 2005; King et al. 2005). There is evidence that district nurses form a key role in community palliative care performing roles of assessment, personal care, emotional care, and care co-ordination (Jarrett et al. 1999, Beaver et al. 2000, Department of Health 2006) particularly early on in the disease
trajectory when district nurses perform ‘early support visits’ (Griffiths 1997; Griffiths et al. 2007; Griffiths et al. 2010). District nurses seem to hold these visits as extremely important for relationship building (Austin et al. 2000) but struggle to express this. Therefore, it has been argued that these ‘invisible’ (Hallett and Pateman 2000) aspects of care provide quality but are unaccounted for. However, this invisibility has only been documented from a district nurses point of view. It is unlikely that patients consider this work ‘invisible’.

3.4 Summary of background literature:

There appears therefore no one single best way or factor to assess for or drive for quality care. Whilst economic assessments may facilitate measuring the physical process and outcomes of care, they are intrinsically limited in their ability to account for the non-physical aspects of care such as compassion. Equally, defining quality entirely from a patient perspective is also intrinsically limited by the virtue that patients must first become viable patients before they can critique their patient experience. Therefore, quality and its production appears to be complex and contradictory and never understood or measured by any of its constituent parts.

Examining the literature it appears that measurements of quality should not aim to replace one way of measuring over another but instead aim to allow multiple perspectives and possibilities for measuring quality. This in itself is a marker of quality by the very virtue of allowing the multiplication of subjectivities formed by novel discourses on quality of care. This position, however, is not naïve of the political pressures to claim improving quality of healthcare and the utilisation of measures and language that are most likely to demonstrate improvement. Nor is it ignorant to the problems that multiple measures would create such as an inability to compare one service with another. However, to delimit that all quality should “relentless[ly] [focus] on outcomes for patients” (Department of Health 2010b) may begin to sideline other important measures and silence patients’ and carers’ views about non-outcome based aspects to care. Whilst the above ideas around quality of care
are important it is necessary to draw in new perspectives analysed in a post-structuralist way to allow this multiplication of subjective positions to occur.

To start this process a systematic review is required to reveal the current discourses of patients’ and carers’ views of quality in district nursing care. This review then goes on to form the basis for the initial interview protocol (appendix B) and to interrogate ‘quality’ of care from a post-structuralist perspective.

3.5 Systematic review

Systematic reviews are a research method designed to search for, evaluate, and synthesise all the available literature pertinent to a research question (Khan et al. 2001; Moher et al. 2009). They have become popular in health sciences as a way of quickly and efficiently evaluating large volumes of research for clinicians (Mays et al. 2005). However, in this thesis, the systematic review is not serving its typical purpose of presenting scientifically rational ‘truth’ ranking individual studies and presenting a weighted synthesis, as may occur in other systematic reviews used for clinical purposes (Hawker et al. 2002; Evans 2003). Instead, the review was used to develop the first draft of the interview protocol and develop an understanding of the current hegemonies around palliative and supportive district nursing care so that they could be opened up to challenge with empirical research.

3.5.1 Search strategy

The search strategy was devised by splitting the literature review question, ‘what do patients and carers find gives quality to palliative and supportive district nursing care?’, into four categories: Quality, district nursing care, palliative and supportive care, patients and carers. These were then mapped onto MeSH headings for the Medline and Evidence Based Medicine databases; and CINAHL headings for CINAHL and British Nursing Index (see table 3.1 for full lists of search terms used).
The date limits were September 2010 back until 1st January 1990 when changes occurred in community healthcare provision due to the National Health Service and Community Care Act 1990 (Great Britain 1990).

After September 2010 other literature, conference presentations, discussions with other academics and the interviews themselves influenced the data collection process and the interview protocol (described in chapter 5), but did not form part of the initial systematic review which is described in this chapter and used to form the initial interview protocol. All the results for each category were combined using the ‘OR’ search term. All four categories were then combined with ‘AND’. Search results were then reviewed for relevance into the study by applying inclusion and exclusion criteria:

- Does it address quality?
- Does it address non-specialist palliative and supportive community nursing care?
- Does it address supportive and/or palliative care?

To assess for this the title and/or the abstract were read, if this was not conclusive the full text was reviewed. Databases were searched sequentially: Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), British Nursing Index (BNI) and Evidence Based Medicine (EBM), duplicates were eliminated. Reference lists were then interrogated and pertinent authors contacted. This resulted in twenty four articles being identified. A flowchart of this process can be seen in figure 3.1. This process was peer-reviewed and any discrepancies were discussed until a mutual agreement was reached.

3.5.2 Data extraction

For this review it was decided to take the understanding that all literature has something to contribute (Paterson et al. 2001; Pawson 2006). This is in keeping with the post-structuralist philosophy of this research which aims not
to privilege one form of knowledge over another and multiplying analytical possibilities.

**Table 3.1 Literature review search strategy**

<table>
<thead>
<tr>
<th>Research question area</th>
<th>Keyword/Cinahl Heading*/Explode^</th>
<th>Combined with</th>
<th>Combined with</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Quality”</td>
<td>Quality Assessment*</td>
<td>OR</td>
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<td></td>
<td>Quality Assurance*</td>
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<td>Quality Improvement*</td>
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<td>Quality Management, Organizational*</td>
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<td>Quality of Care Research*</td>
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<td>Quality</td>
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<td>Quality of healthcare*</td>
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<td>Quality of nursing care*</td>
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<td>Patient satisfaction*</td>
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<td>Satisfaction</td>
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<td>Consumer satisfaction*</td>
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<td>OR</td>
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<td></td>
<td>Carer satisfaction</td>
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<td>OR</td>
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<td>“District nursing care”</td>
<td>Community Health Nursing*</td>
<td>OR</td>
<td>AND</td>
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<td>District nurse</td>
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<td>District nursing</td>
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<td>Holistic Nursing*</td>
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<td>Home Nursing, Professional*</td>
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<td>Home Visits*</td>
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<tr>
<td>“Palliative and supportive”</td>
<td>Palliative care*</td>
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<td>Hospice care*</td>
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<td>Hospice and Palliative Nursing*</td>
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<td>End of life</td>
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<td>Terminal</td>
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<td>Supportive care</td>
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<td>“Patients’ and carers”</td>
<td>Patients*</td>
<td>OR</td>
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<td>Terminally ill patients*</td>
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<td>Hospice patients*</td>
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<td>Service users</td>
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<td>Carers</td>
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<td>Consumers*</td>
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<td>Spouses</td>
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However, this is not to say all literature should be included. Whilst there are multiple truths to be represented and allowing these to be represented is essential in a post-structuralist framework there remain some limits for what can be considered viable research. This basic minimum standard is one which assures the papers are logical and credible. Only one paper (Cowley 1993) failed this test, to the extent that the research process was incomprehensible with different sample sizes being quoted in different parts of the paper with no explanations given for these discrepancies, it was therefore excluded. In addition, because this literature review was being used to develop an interview protocol, and hence was really understood as the beginning of the research process, any formal ranking or evaluation of the literature beyond ensuring it was logical and believable was not considered necessary.

For the literature review no computer based analysis tools were used (unlike for interview transcripts). This was mainly due to personal preference when reading journal articles and the greater difficulty in using computer aided analysis with PDF files. Instead, notes were kept on the main themes of each article using a data extraction sheet (appendix C) these were then compared and contrasted in a data extraction table (table 3.2) to try and understand what themes could be considered common amongst the papers in the review using a notebook to plan out ideas. No efforts were made to find one single overarching theme or develop a formal structure for data extraction as the primary aim was to understand the current hegemonies and produce an interview protocol to challenge them. Where only one paper (Liaschenko 1994) appeared to raise a unique theme it was included as a theme in interviews to try and maintain as much of the data from the literature as possible. Subthemes similarly became subcategories of interview questions. Details regarding design and sample were also noted not to make judgements about reliability or validity but instead help inform the likely requirements for this study.
Table 3.2 Literature review data extraction table

<table>
<thead>
<tr>
<th>Author/ Date</th>
<th>Analysis/data collection method</th>
<th>Sampling method</th>
<th>Number/ Attrition</th>
<th>Setting</th>
<th>Characteristics</th>
<th>Research aim/question</th>
<th>Findings/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higginson (1990)</td>
<td>Mixed Methods - Quantitative and qualitative interviews (developed from literature),</td>
<td>Conveniences Sample</td>
<td>65 first interview, 12 second interview</td>
<td>UK - Patients under care of community team</td>
<td>All cancer patients, mean age = 65; 32-83, 74% spouse, 9% daughter, 6% sister, 6% friend, 5% sons.</td>
<td>To investigate the current problems and needs of terminally ill cancer patients and their family members, and to discover their views of hospital, community, and support team services.</td>
<td>Conflates GP and DN input - rated higher than hospital teams: sympathetic, professional, friendly, willing to visit, discuss problems. Very few negative comments about DN</td>
</tr>
<tr>
<td>Liaschenko (1994)</td>
<td>Post-modern theoretical</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>To explore the Foucauldian concept of 'the gaze' in relation to nursing in the home.</td>
<td>Nurses are key in how care is shifted from hospitals to home and can control the type of gaze used. Home may become an extension of the hospital and reduce patient agency. Does the nursing gaze merely extend the medical gaze? The need for treatment is a social and capitalist</td>
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construction, doing nothing is always an option. Do patients want power being exercised? If so, how?

<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Sample</th>
<th>Country</th>
<th>Characteristics</th>
<th>Purpose</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fakhoury et al. (1996)</td>
<td>Survey – (Chi Squared, Multi-collinearly test) Structured Interviews – RSD</td>
<td>RSCD sub sample</td>
<td>UK - various</td>
<td>46.7% spouse, 31.8% child/grandchild, 15.7% other family, 5.8% friend</td>
<td>To assess whether satisfaction is a reflection of service characteristics, non-service related factors, or attributable to both.</td>
<td>Service variables (i.e. frequency/duration visits) effect satisfaction more than non-service (i.e. place of death, psychological problems). Doesn't assess whether outcome of care was better or not. Relationship building important. Type of service practical/talking not correlated with satisfaction.</td>
</tr>
<tr>
<td>Grande et al. (1996)</td>
<td>Content Analysis - Semi-structured Interviews</td>
<td>Random GP sample asked to identify patients in last year of life</td>
<td>UK</td>
<td>39 Cancer, 2 cirrhosis, 2 respiratory and/or IHD, 18 Men 25 Women</td>
<td>To investigate how patients with a life expectancy of less than one year view the care and support provided by their doctors and nurses.</td>
<td>Psychological care highly valued (sitting and talking, being caring) - difficult to demonstrate impact on outcome of care but patients appreciate the process, clinical care only needs to be 'competent', DN care rated highly, patients may not feel able to ask for emotional support from DN 56%</td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Geographical Location</td>
<td>Recruitment</td>
<td>Study Objective</td>
<td>Findings</td>
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<tr>
<td>Fakhoury et al. (1997)</td>
<td>Survey (Chi Squared) - Postal survey</td>
<td>RSCD sub sample 1858</td>
<td>UK - various health districts</td>
<td>Not stated</td>
<td>To investigate associations between measures assessing bereaved carers' health status and perceptions of the quality of palliative care delivered by community nurses, GPs and hospital doctors to cancer patients in their last year of life.</td>
<td>Carers health status is correlated with the retrospective perception of the quality of care given by DN.</td>
</tr>
<tr>
<td>Jarret et al. (1999)</td>
<td>Thematic Analysis – Semi-structured Interviews</td>
<td>Conveniences Sample, Selected by district nurse 12 patients 9 carers</td>
<td>UK - community 11 cancer 1 MND patient</td>
<td>To explore terminally ill patients' and their lay-carers' perceptions and experiences of community-based DN</td>
<td>DN perceived as hierarchical, confusion over who provides what, high volume of different nurses is frustrating, pt/carers want a relationship/friendship with nurses, informal visits appreciated</td>
<td></td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Setting</td>
<td>Services Provided</td>
<td>Findings and Implications</td>
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<tr>
<td>Lecouturier, et al. (1999)</td>
<td>Statistical analysis (Chi squared) - Postal Survey</td>
<td>156/355</td>
<td>South Tyneside - Deprived</td>
<td>To assess the satisfaction of lay caregivers with the care received in the community by those dying of cancer.</td>
<td>DN frequency/duration/timing important in satisfaction, 66% had DN care, basic nursing care would be appreciated from DN.</td>
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<tr>
<td>Grbich at al. (2001)</td>
<td>Thematic Analysis - Focus groups, In-depth Interviews, Questionnaire</td>
<td>20/25</td>
<td>Death Registers Via HCP</td>
<td>To explore the emotional experiences and coping strategies of a group of caregivers as they move from the diagnosis of a close family member with terminal cancer through the stages of caring and post bereavement,</td>
<td>Conflates DN and other community HCP - Community HCP provide very little post-bereavement support. Role often patient centred not family centred. Need for increased emotional support around bereavement time.</td>
<td></td>
</tr>
<tr>
<td>Stajduhar (2003)</td>
<td>Ethnographic Observation, Purposive</td>
<td>12 patients, 13 family</td>
<td>Canada - Community</td>
<td>To examine the social context of</td>
<td>Patients &quot;fight for quality&quot; at hospital - doesn’t seem to happen</td>
<td></td>
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</table>
In-depth Interviews, Focus Groups | Care | home-based palliative care giving | at home. Maintaining "normal home life" can be hard. When HCP respect carers and their experience it positively impacts on quality of care and they become "part of the family".

Appelin and Bertero (2004) | Phenomenology (Giorgi) - In-depth Interviews | Purposive sample - Approach ed by DN | Sweden | 3 men 3 women | To obtain an understanding of patients' experiences of palliative care at home with service from district nurses | DN provides a safe secure environment. DN are more than just a nurse, they are a "fellow being" (provide fellowship).

Gott et al. (2004) | Thematic Analysis - Focus groups, Semi-structured interviews | Focus groups: maximum variation, Interviews: Purposive | UK - Sheffield, various community groups | Diverse: age, culture, illness/frailty | To explore the attitudes of older people towards home as a place of care when dying. | Maintaining a home as a 'home' is important. Home can be deconstructed by DN involvement and 'strangers'. Patients/carers prefer friendship with a nurse to do personal care and maintain the home as a 'home' not a stranger. Home is symbolic of good end of life care but not essential. Home can be constructed elsewhere.
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Sample Size</th>
<th>Recruitment</th>
<th>Setting</th>
<th>Participants</th>
<th>Research Question</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Grande et al. (2004)</td>
<td>Content Analysis - Semi-structured Interviews</td>
<td>Purposive sample</td>
<td>60 interviews - unknown attrition</td>
<td>Cambridge Hospice at home patients</td>
<td>Cancer and non-cancer, 41 spouses, 15 children, 4 other</td>
<td>To identify what informal carers valued in the palliative support provided by GPs and district nurses by using carers’ own descriptions of such support.</td>
<td>Conflates GP and DN: Valued: continuity/relationship, accessibility (equipment and HCP), enlisting other agencies, attitude/behaviour, support, symptom control</td>
</tr>
<tr>
<td>King et al. (2004)</td>
<td>Thematic Analysis - Semi-structured Interviews</td>
<td>Maximum variation - Via 8 GP surgeries</td>
<td>15/36</td>
<td>UK - Calderdale/Kilkeels. Has 24hr DN service</td>
<td>14 cancer, 1 none cancer, carers of</td>
<td>To explore carers’ experiences of out-of-hours care and support services.</td>
<td>Out-of-hours services greatly appreciated, need for greater communication between services, handover forms help with this. Handover forms don’t transfer relationships only knowledge. Need for non-cancer support registers out-of-hours. DN form a key point of contact out-of-hours (more than GP or Mac) main problem is waiting time. Desire to develop relationship with DN</td>
</tr>
<tr>
<td>Perreault et (2004)</td>
<td>Phenomenology</td>
<td>Purposive sample</td>
<td>10 unknown</td>
<td>Canada - recruited in</td>
<td>Carers: average 69.6yrs old, 3</td>
<td>To explore the experience of family</td>
<td>Highlights poor community follow-up post-A+E visit. DN may stop</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample</td>
<td>Attrition</td>
<td>IPU</td>
<td>Support</td>
<td>Comments</td>
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<tr>
<td>Appelin et al. (2004)</td>
<td>(Heideggerian) – In-depth Interviews</td>
<td>Not stated</td>
<td>18 - 6 patients, 6 carers, 6 DN</td>
<td>Sweden - homes of patients/carers</td>
<td>All cancer patients, age 73.3 range 54-85</td>
<td>A secondary analysis of data to identify the comprehensive picture of palliative care in the home, as experienced by the people involved.</td>
<td>Conflates DN, carer and patient views - Home changes when DN start visiting (more hospital like), more training and support is needed for DN to provide quality care, DN strive to create normality in a home environment but it will always be striving. DN mainly offer medico-technical care, DN need to provide individualised information, DN help but the carer always remains on-call, sometimes poor communication between DN and carer. More resources needed to support visiting after treatment for cancer is completed. More support at home would increase time at home (even if death didn't occur at home). Waiting times problematic, poor transition from oncology to palliative care. Unclear who supports the carer.</td>
</tr>
<tr>
<td>Appelin et al. (2005)</td>
<td>Phenomenology (Gaderian) In-depth Interviews</td>
<td>Not stated</td>
<td>18 - 6 patients, 6 carers, 6 DN</td>
<td>Sweden - homes of patients/carers</td>
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<td>Reference</td>
<td>Methodology</td>
<td>Sample</td>
<td>Setting</td>
<td>Description</td>
<td>Findings</td>
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<td>Exley et al. (2005)</td>
<td>Thematic Analysis – Semi-structured Interviews</td>
<td>Convenienced</td>
<td>29 Patients, 25 Carers.</td>
<td>1/2 large city based ethnic community, 1/2 white semi-rural community. Newcastle community</td>
<td>To explore the views of health professionals, patients and their carers about care provided at the end of life. Cancer patients accessed DN more than cardio-respiratory patients (no figures). Patients’ knowledge of diagnosis/prognosis may impact on their willingness to access care. Cardio-respiratory patients have lower knowledge of diagnosis/prognosis.</td>
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<tr>
<td>Jo et al. (2007)</td>
<td>Unspecified (qualitative coding via literature review and adapted) - Semi-structured Interviews</td>
<td>Convenienced Sample</td>
<td>10/44.</td>
<td>Canada - Community Care</td>
<td>All Cancer patients, 7 male 3 female. 9 dyads received in-home care nursing</td>
<td>To examine the perspectives of both the spousal caregiver and care recipient on the care giving experience in home-based palliative care. Need for more support with physical care, time and continuity (same person and/or information sharing), are key to quality home care. Poor co-ordination and communication decreases the outcomes of care.</td>
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<tr>
<td>Melin-Johansson et al. (2007)</td>
<td>Content Analysis - Focus groups</td>
<td>Unclear - Recruited via p/c nurses/ph</td>
<td>4/16.</td>
<td>Sweden - at a room in a hospital</td>
<td>2 women, 2 men mean age 63 range 53-73, All cancer.</td>
<td>To describe caregivers’ perceptions about terminally ill family Care needs to be “unconditional and qualified”, available 24hrs a day, relationship developed.</td>
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<tr>
<td>Study</td>
<td>Theory</td>
<td>Methodology</td>
<td>Setting</td>
<td>Primary Focus</td>
<td>Analysis</td>
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<tr>
<td>Oudshoorn et al. (2007b)</td>
<td>Critical Theory with Loflands Analytical Coding</td>
<td>Secondary analysis of interviews</td>
<td>17 nurses, 16 patient interviews (derived from 4 patient-nurse-carer triads)</td>
<td>Canada - community care</td>
<td>To elicit an in-depth understanding of the sources of power and how power is exercised within client–nurse relationships in home-based palliative care.</td>
<td>Splits power into macro/meso/micro levels. Macro: Nurses are controlled by fiscal guidelines &quot;get on with physical work&quot; and &quot;be efficient&quot; Meso: Nurses exert power (positional) over patients by virtue of their status, can be possessive/dominating or liberating. Patients, lacking positional power resist power at times (unclear how). Micro: Time directly impacts on relationship building. Nurses control type/length/frequency of visits. Nurses may exert power by 'visiting in their own time'. If nurses are less dominated by fiscal pressures they are more likely to practice liberating</td>
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</table>
Involvement in decisions decreases inequalities at all levels and will improve care. Contracts should be awarded to those who foster relationships with patients, not fiscally efficient care.

<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Sample</th>
<th>Location</th>
<th>Characteristics</th>
<th>Purpose</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selman et al. (2007)</td>
<td>&quot;Qualitative&quot; – (used constant comparative analysis) - Semi-structured Interviews</td>
<td>Purposive sample</td>
<td>UK - Tertiary Hospital</td>
<td>80% male, average age 69 range 43-83, high rate of co-morbidities</td>
<td>To formulate guidance and recommendations for improving end-of-life care in CHF; and to generate data on patients' and carers' preferences regarding future treatment modalities, and to investigate communication between staff, patients and carers on end-of-life issues.</td>
<td>DN not mentioned at all, seems to be a desire to 'keep' patients within cardiology services or at best share with palliative care services</td>
</tr>
<tr>
<td>Hebert et al.</td>
<td>Ethnographic - Interviews,</td>
<td>Purposive</td>
<td>US - Community</td>
<td>27 Female, 6 Male, 10</td>
<td>To determine what questions family</td>
<td>Conflates hospital/community - Suggests that a prompt sheet</td>
</tr>
<tr>
<td>Year</td>
<td>Methodology</td>
<td>Approach</td>
<td>Sample Size</td>
<td>Sample Details</td>
<td>Research Focus</td>
<td>Findings</td>
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<td>2008</td>
<td>Focus groups</td>
<td>sample attrition and IPU</td>
<td>Cancer, 6</td>
<td>cardiovascular, 2 COPD, 1 cirrhosis, 1 dementia, 3 other</td>
<td>Caregivers want to discuss with health care providers in order to prepare for the death of a loved one.</td>
<td>Would help patients to ask questions that they felt unable to ask. Need for more education/encouragement to ask questions.</td>
</tr>
<tr>
<td>2008</td>
<td>Ethnographic - Observation</td>
<td>Purposive attrition</td>
<td>All cancer, 67-75, 2 white, one West Indian, one African</td>
<td>To explore the culture of home-based palliative care as experienced by people older than 65 years who are dying of cancer.</td>
<td>Patients’ homes can be turned into a space of professional domination/power decreasing the home and transmuting it into a medicalised space. This can be decreased by nurses decreasing biomedical discourse and just &quot;being&quot; with patients connecting with patients as friends and people. Friendship may increase homeliness.</td>
<td></td>
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<tr>
<td>2009</td>
<td>Grounded Theory - Semi-</td>
<td>Theoretica l</td>
<td>28-93yrs old 50% male/female, 12 Cancer, 1 neurological, 1</td>
<td>To describe the significant issues that influence the processes of care decision making, from the perspective of GP/Nurse/DN.</td>
<td>Good relationships improve care and support decision making. Relationship effected by: manner and focus of HCP, trustworthiness, culture of HC.</td>
<td></td>
</tr>
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</table>
**Observation**

Is (4 medical, 12 nursing, 2 counselling) unknown attrition

**Heart**

of patients with advanced illness.

**Burt et al. (2010)**

Statistical analysis - Post-bereavement quantitative survey

Random sample of registered deaths 1266 bereaved carers (42.2% response rate)

England Over 65

To compare the experiences in the community in the last 3 months of life of older adults dying from cancer and non-cancer causes.

Non-cancer patients significantly less likely to receive DN care, even when accounting for differences in symptoms. Also significantly less likely to rate DN services as good or excellent.

Environment, taking time. Being patient focused isn't an overt text, it is a sub-text that is read by peoples actions. Niceness is important to patients - suggestion that niceness is symbiotic between patient and nurse.
Figure 3.1 Literature review process

- Initial results
  - Medline: 541
  - Cinahl: 72
  - BNI: 10
  - EBM: 75
  - Reference Tracking: N/A
  - Author Contacting: 2

- Included after title/abstract reviewed
  - Medline: 42
  - Cinahl: 9
  - BNI: 3
  - EBM: 0
  - Reference Tracking: 3
  - Author Contacting: 1

- Included after full text review
  - Medline: 16
  - Cinahl: 3
  - BNI: 2
  - EBM: 0
  - Reference Tracking: 2
  - Author Contacting: 1

Total: 24
3.6 Literature summary

Five core themes emerged from examining the literature that may affect patients’ and carers’ construction of quality palliative and supportive district nursing care, namely: relationship, continuity, maintenance of the home environment, access, and communication. These are presented below, at times making reference to other pertinent literature which whilst not found via a formal literature review, still offers a useful insight into the literature review question.

3.6.1 Relationship:

Eleven studies were identified that discussed how relationships between patients and carers, and district nurses affect quality of care. Three sub-themes are identified: construction of the relationship (Jarrett et al. 1999; Stajduhar 2003; Appelin and Berterö 2004; Gott et al. 2004; Jo et al. 2007; McWilliam et al. 2008); structures that influence the relationship (Fakhoury et al. 1996; Lecouturier et al. 1999; King et al. 2004; McWilliam et al. 2008; Lee et al. 2009); and processes that influence the relationship (Stajduhar 2003; Gott et al. 2004; Grande et al. 2004; McWilliam et al. 2008; Lee et al. 2009).

Constructions of relationships:

Patients construct relationships with district nurses as: friends or having a friendship (Jarrett et al. 1999; Gott et al. 2004; McWilliam et al. 2008), almost friends (Jo et al. 2007), a fellow being (Appelin and Berterö 2004), or part of the family (Stajduhar 2003). Only one study found negative constructions of district nurses where they were described as strangers, where there was a high volume of different nurses (Gott et al. 2004); suggesting overall that patients’ and carers’ constructions of district nurses are couched in positive conceptions despite there sometimes being negative experiences.

Literature from a patient and carer perspective focuses more on the nature of the relationship rather than its function. In contrast the literature from a district nursing perspective places more importance on function in the form of ‘early
support visits’ directed at maintaining and building relationships and psychological support (Austin et al. 2000; Griffiths et al. 2007; Griffiths et al. 2010). How this reconceptualisation affects patients’ views of quality nursing care has not been fully investigated. For example, it is not known why patients would choose to conceptualise nurses as ‘friends’ and how this impacts on the quality of their care. If nurses are being pushed to develop justifiable and measurable nursing interventions this is clearly at odds with the patients conceptualising the caring relationship as a friendship. Whilst not all patients may conceptualise their district nurses as friends, examining what factors lead to varying conceptualisations may aide nurses to adapt their role to the patients’ needs and desires rather than political rhetoric.

*Structural influences:*

The frequency and duration of district nursing visits appear to alter the way a relationship develops (Lecouturier et al. 1999, King et al. 2004, McWilliam et al. 2008, Lee et al. 2009) but the mechanisms for this are not considered (Fakhoury et al. 1996). For example, it is not known which comes first, the positive relationship which may influence the nurse to spend more time with particular patients; or the increased time spent with patients or carers which may increase the quality of the relationship. McWilliam et al (2008) suggests that it is the latter and that the nurse-patient relationships is shaped by fiscal and policy pressures. This in turn influences nurses to practice in a “dominating” manner, because they themselves are being dominated by structural forces. This reduces the quality of the relationship. She suggests that by changing the structural forces to measuring the quality of relationships that are fostered, nurses would practice liberating nursing which improves the quality of the client-nurse relationship. However, this points to a linear relationship of cause and effect. Li (2004) suggests that the nurse-patient relationship is instead symbiotically built. She argues that niceness “simultaneously requires, feeds on and ‘grows’ from the niceness of nurses themselves and of patients and nurses…” (Li 2004: 2577). This makes both nurses and patients responsible for the quality of the relationship. This in many
ways is similar to the theoretical conclusions of chapter 2 where responsibility for moral/quality care lies with both subjects. However, neither of these papers theorise any ways in which the structures of care may be altered to foster these relationships, something that requires further empirical research.

Process influences:

Literature exploring process influences on the quality of the patient-district nurse relationship is less prevalent. What does exist suggests a need to change the nature of the nursing role. McWilliam (2008) suggests that biomedical discourses reduce the quality of the relationships and create a power divide with patients. She suggests instead that nurses just ‘be’ with the patients, thereby connecting with them as friends and as people. This can be seen as enhancing the ‘homely’ nature of the home which can otherwise be disrupted by nurses introducing a biomedical discourse which is foreign to the home environment (Gott et al. 2004, McWilliam et al. 2008). A friendly rapport has been found to build trust between patients and carers (Grande et al. 2004), and that when healthcare professionals respect carers’ expertise they become “part of the family” (Stajduhar 2003: 32). These findings suggest that splitting personal care and nursing care is undesirable because it will dilute any relationships that develop. It also suggests that the relatively new role of community matrons who “[manage patients with] numerous long term conditions and complex needs” (NHS Care Records Service 2011) may reduce the time for district nurses to build a relationship with patients with chronic diseases by negating their presence earlier in their disease progression. It is possible that this would result in a poorer relationship being established by the time district nurses are required for nursing care at the end of life. How this affects the quality of care has not been researched. In addition re-reading these findings through the theoretical framework in chapter 2 it can be understood as moral when patients and carers subjectivities are allowed to redevelop when nurses become something else such as ‘family’ and ‘friends’.
To summarise, in general, patients’ views on relationships are under-represented in the literature with only six studies investigating patients’ views and nine investigating carers’ views. This small number of studies with a higher number focussing on carer views, as valuable as district nurses caring for carers is, fails to consider how ‘patient centred care’ may operate in district nursing (Department of Health 2008). Such a paucity of research may result in patients’ voices being silenced in ‘evidence based practice’ in turn restricting what is viable for patients to be, say and do. It is possible that this bias has emerged for pragmatic reasons; that it is easier to find and interview bereaved carers retrospectively rather than prospectively interview patients with terminal illnesses (Fakhoury et al. 1997; Lecouturier et al. 1999; Scott et al. 2001; Grande et al. 2004; Young et al. 2008; Grande and Ewing 2009). However, research suggests that carers proxy views often differ from the patients views, particularly in relation to psychological distress and pain (Wilkinson, Salisbury et al. 1999). Therefore, if care is to be ‘patient centred’ it is logically necessary to research patients’ views in this research study. Carers' views are sought only to provide contrast as carers, not as a proxy for patients.

3.6.2 Continuity of care:

Four studies directly discuss continuity of care and its affect on the quality of palliative and supportive care patients and carers received from district nurses (Grande et al. 2004; King et al. 2004; Jo et al. 2007; McWilliam et al. 2008). This was difficult to distinguish from the previous theme ‘relationships’ because patients felt it was important to have the same person carrying out the care (Grande et al. 2004; Jo et al. 2007). It is difficult to assess in the literature whether it was continuity of care or whether it was the relationship between patients and/or carers with their district nurses that improved the quality of care. Therefore, to tease out this particular paradox it may be helpful to ‘split’ continuity as Saultz (2003) does into two different aspects: information transfer and relationship transfer. Whilst a third aspect of continuity ‘managerial’, is added by Haggerty et al (2003), conceptualising continuity in this way does not appear to help tease out the difference between a
relationship with a patient and knowledge of the patient. Therefore, for the purposes of this section, managerial continuity is not considered.

In palliative and supportive district nursing there are several information ‘transfers’ that have to happen: between in-hours and out-of-hours services; inter-disciplinary such as oncology to palliative care services; and between different professionals within the same discipline. Whilst interventions can be introduced to enhance the transfer of information, it is difficult to transfer relationships that patients built.

Jo et al (2007) and Grande et al (2004) suggest in their qualitative studies, conducted respectively in Canada and the UK, that it is highly desirable to have the same person performing palliative and supportive care and that it can lead to patients feeling someone akin to a friend is performing the care. However, achieving continuity of a small number of individuals over different times of day in the mid to long term is problematic, particularly for district nurses where research suggests they are the most commonly contacted professionals out-of-hours in the community (King et al. 2004). There may also be a culture of ‘safe guarding’ patients from bad out-of-hours experiences by giving out personal contact details. In King et al’s (2004) study whilst nearly all patients had the official out-of-hour contact details, five out of a sample of fifteen also had the personal contact details of their GP or district nurse to be called in a crisis. King et al (2004) report that patients found this reassuring but never actually used this option. Why healthcare professionals had chosen to give these details can be read in two ways. It could be read as a devoted gesture to this group of patients empowering them to stay at home (Fox 1993) or as a way of gaining power and influence over them (McWilliam et al. 2008). It is likely that the truth lies somewhere between these two interpretations.

More importantly it poses questions over how far professionals are willing to go to maintain continuity of care within a system that has either contracted out-of-hours care to secondary care providers or gives inadequate service provision. It also poses questions about the professional limits of the relationship that patients have with their healthcare professional, and if by striving to increase continuity of healthcare they become either an invasive presence in the home or a close friend. The former may reduce the very
qualities of the home environment that motivated people to choose a home care option whilst the latter may risk placing professionals in discursively unviable territory.

To counter these difficulties, models of district nursing (Department of Health 2008, 2009a) with large in-hours teams and smaller (if any) out-of-hours teams working relatively separately may need to be adapted to provide care if the government’s aim of increasing home deaths are to be realised. Continuity for palliative care out-of-hours in the community often relies on handover forms (King et al. 2004), whilst this improves information transfer between in and out-of-hours services, the transfer of a therapeutic relationship is lost; and with current legislation allowing any willing provider to bid for contracts how continuity can be achieved must be considered.

Much may be learnt from other healthcare disciplines such as midwifery service provision. Since the Maternity matters report (Department of Health 2007) the community midwifery services in King’s College Hospital have adapted to increase the choice and the number of home births (Porter 2010). Two teams with six midwives in each have been created. The patients of the midwives are attached to one of either two teams. They usually have contact with all six of the midwives in the team over the course of the nine month pregnancy. The team works on a rota basis between days and nights. This results in a system where patients can almost always access a midwife that they have a relationship with. This has resulted in home births being “an every day event” (Porter 2010), not a statement associated with home deaths. Whilst service provision for palliative care may be more complex with patients requiring several visits a day for several weeks or months, novel solutions such as rotations between in and out-of-hours services may give both continuity of information and relationships. By increasing both aspects of continuity as described by Saultz (2003) it is possible that quality of care will be improved. However, further research is required to establish such links and examine how it might function in current district nursing management.
3.6.3 Maintenance of a home environment:

Home care for patients with palliative and supportive needs is often considered a quality outcome indicator (Department of Health 2009a). Six studies were found to relate to how patients and carers feel the home environment is maintained and how this affects quality of care. This can be split into two sub-themes: how technology in the home affects the home environment (Liaschenko 1994); and how nurses constructions of their role affects the home (Liaschenko 1994; Gott et al. 2004; Perreault et al. 2004; Appelin et al. 2005; McWilliam et al. 2008). Whilst the literature highlights maintaining the home as an important aspect to patients and carers, less work has been done on how it affects quality of care.

Technology in the home:

There is little published research that describes the exact equipment that is used at home at the end of life and any differences between countries. Whilst access to equipment is cited as a problem in providing home care (O’Brien and Jack 2009) research has not addressed the value or utility of various equipment, why, and for whom, nor has it considered other technologies such as call systems and medications. Liaschenko’s (1994) work on the moral geography of care suggests the amount of technology at home (in America at least) has been increasing. This affects the nature of the home transforming it into an extension of the hospital both practically and existentially where “the agency of the dominant practitioners is preeminent” (Liaschenko 1994: page 17). Therefore, whilst the provision of an increasing amount of medical technology and equipment may be done in a spirit of maintaining the patient in a house, the home may become subverted. However, this is a broad generalisation and it is possible that different pieces of equipment and technology have different affects depending on their context. This leaves important questions to answer about how increasing technology may (re)form the ‘home’ environment and how district nurses may in turn negotiate and (re)form the subjectivities of patients and carers in a moral way through
technology. Further research on the home may also address how this reformation of the home environment not only (re)forms patients and carers but dialectically reforms the district nurse.

**Professional conceptualisations of home care:**

Liaschenko (1994) suggests that nurses have two ways of conceptualising the care they give. They can either conceptualise their care in a biomedical framework focused on a patient’s body, or as supporting an individual person in a unique home (Liaschenko 1994). She suggests that it is not what physical technologies are in place in the home, but the social construction of the home that influences the way nurses conceptualise their care. This also leads to the conclusion that if the home is considered a social construction, then it is not actually the physical place that matters but the symbolism of comfort and normality (Liaschenko 1996; Gott et al. 2004). District nurses must therefore maintain this symbolism whilst creating an adequate healthcare environment to mediate modern nursing care in (Liaschenko 2000). Several authors have touched on the qualities that can help foster this type of environment such as: reducing the medico-technical language that nurses use (Appelin et al. 2005); learning how to “just be” with patients and carers (McWilliam et al. 2008); and making non-task orientated visits (Perreault et al. 2004; Griffiths et al. 2010).

In summary this research tentatively suggests that the continual reconstruction and maintenance of the home environment between the patient-carer-nurse triad affects the quality of care that patients receive. Clearly, a lot of this work remains theoretical in nature and examining it in empirical research can help link theory and practice. Key areas for qualitative research to address would be: patients’ and carers’ views on how palliative and supportive home care is affected by differing professional conceptions of care, how the implementation of technology in the home affects the quality of care, and how patients and carers may resist medicalisation of the home. Understanding these elements will help nurses to implement quality palliative and supportive nursing care by not subverting and even promoting the home environment in new and
innovative ways expanding what ‘the home’ is and how this can be done in a way which can still be considered moral.

3.6.4 Access

Eight studies were found that related access to quality of care. These can be split into two sub-themes: access to equipment and services (Jarrett et al. 1999; Wiles et al. 1999; Stajduhar 2003; Grande et al. 2004; Perreault et al. 2004; Melin-Johansson et al. 2007), and access based on diagnosis (Exley et al. 2005; Selman et al. 2007).

Access to equipment and services:

If patients are to receive quality nursing care, they first need to be able to access the service. There is a lack of research assessing what factors affect accessibility in non-specialist palliative and supportive care despite the strong rhetoric in government documents to increase access palliative and supportive care (Department of Health 2008, 2009a). Whilst the need for access to equipment has been recognised as a problem in the literature (Wiles et al. 1999; Grande et al. 2004), no literature has been identified that describes how access to equipment and services affects quality of care. However, some key points have emerged that may merit further investigation, such as that of accessing palliative care services versus accessing generalist services. Perreault et al (2004) in their Canadian study of patients admitted to an inpatient hospice found that many patients found the accident emergency department was the best place to access palliative care when at home. Often because waiting times particularly in rural areas were excessively long. This shows the important distinction accessing healthcare staff (in this case accident and emergency staff) and accessing an appropriate service (in this case palliative care). It is possible that this is also at times due to confusion over who offers what care (Jarrett et al. 1999, Perreault et al. 2004) rather than simply a lack of service provision. However, within this the term ‘appropriate’
needs to be problematised. Whilst from a provider perspective such care may be inappropriate, it does not follow the same is true from patients’ and carers’ perspectives. Nor has it been explored what regimes of truth dictate why care can be understood as appropriate or inappropriate. It may be that for patients the rapidity of accident and emergency care is appropriate, even if the setting is not.

**Access based on diagnosis:**

Burt et al (2010) found in a large post-bereavement survey that patients with non-cancer diagnoses were significantly less likely to receive district nursing care and also significantly less likely to rate their district nursing services good or excellent. These differences could not be accounted for by adjusting for the differing needs of the patients and were unable to conclude any possible reasons for this disparity. Qualitative studies by Exley et al (2005) and Selman et al (2007) similarly found that the diagnosis and prognosis of a patient with palliative care needs affects the amount they access care district nursing care. They found that cancer patients felt more able to ask for help than patients with non-malignant diseases requiring palliative care and also that patients with chronic diseases tend to be ‘kept’ by their regular healthcare professionals. They tentatively suggest that this is for two reasons. Firstly that patients with chronic diseases felt that if they asked for help it was an admission of failure on their behalf, and secondly that the patients with chronic diseases often had different levels of awareness regarding their diagnosis and prognosis to cancer patients.

To summarise, whilst literature on access to palliative care is limited to a small number of qualitative studies it appears that timely uncomplicated access to care and equipment based on need, not diagnosis, is problematic in several countries such as Sweden (Melin-Johansson et al. 2007) and Canada (Stajduhar 2003; Perreault et al. 2004). The same is likely to be the case in the UK but little research evidence exists in the field of palliative and supportive
district nursing care. Whilst several areas pertinent to access have been highlighted in the literature on palliative and supportive district nursing care such as patients’ and carers’ ability to access care. Further research is needed to address how subjectivities can be reformed in ways which legitimate greater access to palliative and supportive care from district nurses.

3.6 Communication:

Only three studies were found that related directly to how communication affects quality of palliative and supportive district nursing care (Grande 1996; Oudshoorn et al. 2007a; Hebert et al. 2008). Two of these studies examined how barriers to communication could be overcome (Oudshoorn et al. 2007a; Hebert et al. 2008) and one (Grande 1996) examined the value of communication from the patients perspective.

The current tide of communication models seems to put the emphasis on the patient ‘leading’ and ‘guiding’ the practitioner in the conversation (Faulkner 1998, Fallowfield et al. 2002, Connolly et al. 2009). It is generally assumed that this prevents unwanted information being disclosed to the patient. However, much of this research has been theoretical and addresses healthcare professionals concerns of how to conduct conversations. Hebert et al’s (2008) ethnographic study examined carers views. They found that carers often wanted to discuss a very wide range of issues from medication management to the dying process, but found it difficult to articulate their concerns. They developed a prompt sheet covering a broad range of issues from medical, practical, psychosocial and spiritual issues to help carers articulate these questions to healthcare professionals. This clearly goes against the grain of teasing out individual narratives from each patient and carer. Such a prompt sheet could be read as allowing subjectivities to exceed allowing novel discourses to form the patients and carers subjectivities. As long as such a proforma is used to expand subjectivities and encourage patients and carers to think other, rather than delimit a new set of restrictions
outside of which nothing can be spoken, then such tools can be considered moral in nature. Importantly, such arguments should not be used as a reason to disregard previous research but stimulate further research from a patients’ and carers’ perspective on how the underlying philosophies of communication may affect quality of care.

Grande et al (1996) reform the concept of communication from a utilitarian one where information is gained by assessing the patient, to an informal ‘chatty’ approach which is beneficial but not necessarily as measurable. This is in agreement with other literature on district nursing communication from a nurses’ perspective (Mok and Chiu 2004; Griffiths et al. 2007; Griffiths et al. 2010). Oudshoorn et al (2007a) suggest another barrier to good communication lies with nurses experiencing structural pressures which direct district nurses into providing cost effective physical care. This reinforces the idea that merely sitting and talking (and not focusing on providing cost effective physical care) can be beneficial for patients (Grande 1996).

To summarise the literature on communication and its relationship to quality of care appears confused about what communication should be for. If the argument is accepted that healthcare should be focussed on the benefit of the service users, often patients, then it is acceptable for patients to spend time ‘chatting’ with district nurses. However, if the opposite argument is accepted that communication should be for assessment of patients by professionals, then it may be helpful to develop standardised assessment protocols. Clearly such a dichotomy is not necessary and it is possible for communication to serve both the needs of the patient, carer, and the professional. However, policies, theory and practice may skew the nature of communication one way or another. If economic pressures to achieve measurable outcomes continue to be pushed in palliative care, the nature of communication may be directed more towards optimising patient assessment by professionals. How this would affect the quality of care that patients’ perceive has not been investigated. Research is required to more fully understand the nature of communication in such a way as to allow such practices as ‘chatting’ to be more rigorously justified.
3.7 Summary:

Within the literature on quality of care in district nursing there are five extant themes: relationship, continuity, maintenance of the home environment, access, and communication. These themes serve as a starting point to begin to interrogate the *hegemonies* of quality district nursing care with post-structuralist theory. Whilst a small number of studies have a similar theoretical understanding of quality such as Li’s (2004) understanding of symbiotic niceness and Oudshoorn’s (2007a) understanding of power relations in district nursing; both of which used theoretical concepts to analyse the data. Most of the studies in the literature review utilise thematic analysis, grounded theory and phenomenological analysis, with a small number of quantitative surveys. This is not to say that these analyses are unproductive, in the case of this literature review they have helped produce an interview protocol. However, the strength in using theoretical concepts is that it encourages a ‘thinking otherwise’ which would not occur with methods such as thematic analysis alone, enabling the researcher to challenge the current ways of being and thinking about the data (MacLure 2010; MacLure et al. 2007). Therefore, any further research into this field requires the use of theoretical concepts to drive analysis away from everyday analyses and into more challenging areas.

One of the general limitations of the literature in this thesis was that many of the papers conflated district nursing care with other community healthcare professionals (Higginson et al. 1990; Grbich et al. 2001; Grande et al. 2004; Appelin et al. 2005; Hebert et al. 2008; Lee et al. 2009). Whilst it was generally clear which healthcare professional was saying what, it was not always clear for example, whether district nurses and general practitioners had different opinions. Therefore, a research project specifically addressing district nursing care in depth will help add to the body of literature about the quality of district nursing care rather than community care in general. Further empirical research examining these areas would help to understand how district nursing specifically is represented and understood by patients and carers.
Chapter 4

Methods: Underlying theoretical considerations

4.1 Summary of research question

The aim of this research is to investigate patients’ and carers’ views of quality palliative and supportive care. The possible methods to achieve this are only discussed within the context of post-structuralism which has been explicated, critiqued and justified in chapters 1 and 2. To do otherwise would mean debating methods which are incongruent with post-structuralism leading to ultimately fruitless discussions. Therefore, methods such as quantitative surveys and other forms of more structured qualitative analysis, whilst recognised as having academic and clinical value, fall outside of this underpinning philosophy and are therefore not discussed.

4.2 Introduction

This chapter aims to explore the strengths and weaknesses of different methods and how they can serve the research question. In chapter two the argument was made that subjects reside within extant discourses transmitted by language. Therefore, the very basis of this thesis’s methodology must be a concern with language. Without wishing to reinforce the divide between qualitative and quantitative methodologies, to produce an argument that numbers and statistics can unilaterally investigate the discursive frameworks of subjectivity on a moral level is untenable. Whilst it may be possible to ‘survey’ what positions people take up, examining the ways in which these subjectivities affect and are affected by language would not be possible via a
quantitative methodology. As the theoretical framework pushes the research to examine how discourses produce or preclude moral actions, methodologies are needed that are able to analyse discourse and language and its complexity in forming subjective positions. This is best achieved by qualitative methods.

Two qualitative research methodologies are used in this thesis to achieve this aim, thematic analysis (as expressed in the initial stages of grounded theory) and a Butlerian influenced discourse analysis. The former was used to develop the interview protocol and organise data whilst the latter was used to read the empirical data in line with the theoretical framework in chapter 2. To be clear, neither approach is followed fully, instead the concept of ‘bricolage’ is used put forward by Denzin and Lincoln (2000) which argues for a blending of qualitative methods. Therefore, whilst the terms ‘grounded theory/thematic analysis’ and ‘discourse analysis’ are used throughout the thesis, it is important to understand that this is not a grounded theory nor a discourse analysis work.

The methods are a bricolage of two distinctly different research approaches to counteract each of their respective strengths and weaknesses. Discourse analysis, in particular forms influenced by Butler’s theories, whilst producing novel and challenging analyses have been criticised for lacking the tools required for facilitating analysis (Scharff 2011) and in addition lack clarity in methods that are presented (Cheek 2004). In contrast, the thematic analysis as used in grounded theory has a clear tool box to produce an analysis (Glaser and Strauss 1968; Glaser 1978, 1998, 2002; Charmaz 2006) but lacks the abstraction of post-structuralist forms of discourse analysis leading to a criticism that it merely reproduces rather critiques and transforms any social structures (Burman and Parker 1993). Grounded theory, as admitted by Glaser discovers social processes (Glaser 1998). This remains true even if new ‘theory’ is developed (which often grounded theory studies stop short of) because the discovered theory about a new social process remains literally grounded in rather than critiquing and reforming the basic social structures where the research was conducted.
Other qualitative methodologies such as phenomenology and ethnography were considered. However, it was felt that the coding processes of grounded theory provided the clearest methods to develop interview protocols; whilst discourse analysis provided the tools to implement the theoretical framework in chapter 2. Therefore, thematic analysis and discourse analysis approaches will now be discussed at a theoretical level in relation to the processes that need to be undertaken within this research project, namely: sampling, data production, morality of production, analysis, and rigour and validity. Chapter 5 discusses the application, critique and development of the theory behind the methods.

4.3 Sampling

Qualitative research often assumes the position of theoretical sampling where participants are approached who may help fill gaps in the researcher's theory (Glaser and Strauss 1968). However, as discussed this risks privileging the social world being investigated as the driving force of data collection, restricting sampling and the subsequent data analysis within the dominant discourses of the social world concerned. Such an approach risks repeating, rather than challenging and developing academic thought (Burman and Parker 1993) and by extension the care associated with it. To do so, within a post-structuralist ontology would be considered immoral by preventing novel subjective positions to be taken up. Whilst these positions must still be viable (i.e. some restriction must still occur) the restriction that occurs would be reduced if the social world is rejected as the driving force for sampling. Instead, alongside the social extant world, research and theory needs to be interrogated to help sampling exceed what it was originally concerned with, at times sampling from alternative sources to further explicate the historicity of discourses (Clarke 2005). Therefore, sampling need not only remain with research subjects who provide empirical data but may expand to include, for example, art, media, journalism, film, and philosophy.
In relation to palliative and supportive care research, studies have often recruited mainly or exclusively cancer patients. Whilst some studies justify this by specifically addressing cancer patients with palliative and supportive care needs (Lecouturier et al. 1999; Melin-Johansson et al. 2007; McWilliam et al. 2008), many make no such claim yet fail to achieve recruiting much beyond single percentage points of non-cancer patients (Grande 1996; Jarrett et al. 1999; King et al. 2004; Appelin and Berterö 2004; Appelin et al. 2005; Jo et al. 2007; Lee et al. 2009). Some authors have suggested that this lack of representation is due to the misunderstanding of palliative and supportive care by the healthcare professionals who recruit for studies (Ewing et al. 2004).

With 33% of people dying from circulatory disease, 27% from neoplasms, and 14% from lung diseases (Office of National Statistics 2008) it draws into question how representative studies are of the whole palliative and supportive care population where non-cancer patients are under-represented. Whilst sampling in this research does not aim for statistical representativeness, this cannot be used to justify not making efforts to represent those who may be harder to recruit because of a very narrow definition of palliative care that is held by some healthcare professionals (Ewing et al. 2004). Therefore, sampling can aim to improve on previous research by: making additional efforts to sample from a wider population; through using a variety of means; and by explicitly stating that the research is open to all patients regardless of diagnosis.

Much qualitative research relies on the notion of ‘data saturation’, where the stability of categories is synonymous with data collection being complete, therefore determining sample size (Glaser and Strauss 1968; Ayres 2007). However, saturation has not been interrogated from a post-structuralist perspective. When considering theoretical saturation within a Butlerian post-structuralist framework the notions of data saturation occurring when themes become stable is untenable. Post-structuralism posits themes can never be stable as any discourse (which a theme is) requires constant reiteration and (re)performance, making all themes intrinsically unstable. Therefore, if ‘stable’ themes are found it should be read as being indicative of data production being incomplete driving the researcher to search for what produces this
apparent stability. Instead, saturation occurs once stability has been accounted for not when stability is apparent.

4.4 Data production

The term data production reflects the fact that within post-structuralism, discourse simultaneously produces and makes intelligible texts and subjectivities. Therefore, texts are not gathered or collected, to do so would suggest that somehow ‘the researcher’ is outside the text and able to gather but not be involved in the data personally. Data production therefore reinforces in terminology the deeply dialectic nature of data within a post-structuralist theorisation of research. By drawing this conclusion data production becomes something beyond merely a co-construction (Charmaz 2006). Such co-constructive methods whilst accounting for how participants may offer a multitude of social realities fails to account for how participation alters the reality of the subject. A post-structuralist approach to research therefore must take into account that research itself dialectically produces both texts to analyse (i.e. interview transcripts) and subjectivities in the production of those texts, in this case researcher and participant. Therefore, within production of the data, patients and carers taking part in this research will cease truly being patients and carers and instead will exceed their subjectivities becoming patient-participant, and carer-participant. This research therefore cannot truly be titled “patients’ and carers’ views of quality palliative and supportive district nursing care” instead it may more properly be termed “patient-participants’ and carer-participants’ views of…”. This places an intrinsic limit on this and any study research study. To an extent this problem could be circumvented by covert forms of ethnographic research. However, such methodological approaches are likely to pose equally difficult ethical problems where consent cannot be sought. Instead, it seems better to just return to the understanding that being researched produces effects which are not fully accountable for in the research.
4.5 Morality of production

If allowing patients to exceed their subjectivity is moral, is all palliative care research intrinsically moral? De Raeve (1994: 304) argues against any research on palliative care patients suggesting that it is “an affront to the dignity of those people who are terminally ill… there are some questions that we should never ask… maybe the only respectful position is to simply and gratefully receive what is generously and spontaneously offered, rather than to ask”. This position however is built on several at best arbitrary and at worst erroneous premises. Firstly, de Raeve assumes that ‘terminally ill’ is a clearly definable identity and that people can be filtered by researchers identifying them as terminally ill. She suggests that it can be defined as those who “no longer respond to curative treatment and who are deemed likely to die within six months” (de Raeve 1994: 300). This relies on a professional identifying and fixing participants within a discourse of ‘terminally ill’ that patients themselves may not identify with. Such an interpellation forcibly restricts patients subjectivity with a discourse that is not of their own making producing them as being unviable research subjects with no recourse to reforming their identity. By post-structuralist standards this is an immoral act in itself.

Secondly, de Raeve assumes that there are some questions which simply should never be asked, instead waiting for what is spontaneously offered. Such a position does not account for the ways in which social interaction takes place. Within chapter 2 (theoretical underpinnings) it is argued that one never merely acts, all acts can only be considered reactions. Therefore, to suggest that something can be spontaneously offered would suggest that these offerings arise independently of any questioning, and hence any social interactions. Whilst questioning and the acts of the research could be kept to a minimum, it is impossible to produce any act which is not a reaction to some extant discourse enacted by the researcher-subject. This therefore, makes spontaneous offerings a false premise about the research process and therefore cannot be used to justify not researching palliative care patients.

Thirdly, de Raeve’s arguments appear to be based on a distaste for discussing death and dying “about death and dying… one wonders whether they
[terminally ill patients] should ever be asked” (de Raeve 1994: 304). Such an opinion appears more personal rhetoric and appears to reflect the authors own personal ‘comfort zones’ in what she is willing or not to discuss with another person. Whilst this is perfectly justifiable on an individual level, to apply such an argument to all people in the way that de Raeve does is a flawed argument in that it fails to recognise the therapeutic value patients and carers report experiencing (Bellamy et al. 2011; Koffman et al. 2012). This implies a truth in the ‘vulnerable’ identity, forcibly and immorally interpelling patients (and carers) as vulnerable research subjects who need protecting rather than offering alternative positions such as participants benefitting from research and being autonomous enough to protect themselves.

Research into palliative and supportive care and patient participation is therefore just as easily justifiable as any other research, ’special’ exclusions need not apply, and research should aim to encourage participants to discuss novel topics that they may not have spoken about, thereby broadening the boundaries of their subjectivity. This is not to say that issues around death, dying, and the future can be assumed to be discussed in the same way as what one had for lunch; though importantly if participants do discuss these issues in such a matter-of-fact way, an interviewer should aim to work within this understanding. However, in general these topics have been found in other research to be potentially distressing (Gysels et al. 2008) and therefore thought must be given to how distress can be minimised and prevented as far as is possible. When considered in relation to this research project and the particular situations that may be faced, it seems appropriate to draw on communication theory in relation to palliative and supportive care to help inform the morality of the data production.

Faulkner (1998) suggests best practice in delivering ‘bad news’ to patients is to give small amounts of information responding to the patients’ reactions and questions before giving further information and only giving information in so far as the patient expresses a wish to know it. In this way, it is suggested that the healthcare professional will do no harm to the patient. This model can be employed when interviewing research participants where questions are tailored to the participant’s responses, and where possible using the
participants’ words and language. However, in using the same language it is important to make sure that there is a shared understanding of key terms in order to prevent subsequent analyses being read in ways that are misrepresentative of the participants’ views.

Even when using such a framework, it may still be possible that ‘distress’ occurs. However, one must question what exactly is meant by distress, and whether it is a purely negative process. If distress is considered as any form of negative emotion being portrayed such as crying, then it may be highly likely to occur within palliative and supportive care research. However, such emotional distress, if under the control of the participant with the researcher reacting to them by using language which they use, not aiming to ‘push’ one particular question; then distress may instead be read as something which allows emotional release and is a positive experience for participants (Gysels et al. 2008; Bellamy et al. 2011). Distress arising from participants own words and experiences when in an interaction with the researcher cannot therefore be considered immoral and instead distress may then more fully be understood as directing participants towards discussing specific topics which they do not wish to discuss.

4.6 Consent

Consent within palliative and supportive care studies requires particular attention to the potential for participants’ health and ability to consent to change, either before or during the interview (Addington-Hall 2002). Whilst it is a requirement of ethics review boards to have paper or audio recordings of consent for the initial consent (National Patient Safety Agenda 2011). Consent is not as simple as securing a signature and initials on the consent form designed in accordance with NRES guidelines (National Patient Safety Agenda 2011) (appendix D [patient] and E [carer]). Instead consent needs to be considered as a continual process (Munhall 1988). Firstly, it must be made clear from initial contact of the participant with the researcher that it is acceptable to withdraw at any point prior to or during the research. If any factor
appears to change during the research process such as distress, fatigue or pain it is important for the researcher to assess for consent again.

Whilst reassessing the participants consent is highlighted by Munhall (1988), if data production is understood as dialectic, then by extension consent must also be dialectic; meaning that both participant and researcher must consent. Therefore, whilst no formal overt declaration is signed by a researcher the idea that consent may be withdrawn by the researcher must be recognised and accounted for. For example, it is possible that the researcher may become emotionally distressed or upset during an interview (Seymour and Ingleton 1999; Lawton 2000). Putting safeguards in place to deal with such events are just as important as those which are provided for participants.

Coercion within recruitment also needs to be interrogated. Whilst it was made clear on the information sheet that participation or non-participation would in no way affect clinical care, it cannot be assumed that participants can make a distinction and there is a possibility that participants may feel obliged to take part by those who offer them healthcare. Neutrality even from healthcare professionals cannot be assumed, and whilst often the problem is under-recruitment and lack of offering opportunities to take part in research (Ewing et al. 2004), it is possible the opposite could occur.

Therefore, consent in palliative care studies differs little to other studies in so far as it must be free and informed. Peer review of the procedures can help ensure this, but the practices of the researcher (as described in chapter 5) are the key to ensuring the research remains ethical.

4.7 Data production tools

Once sampling strategies and ethical considerations have been established that are consistent with a post-structuralist approach to research, what tools of data production can help serve this research project?
4.7.1 Observational methods

Observational methods can produce revealing accounts of palliative care (Glaser and Strauss 1966; Lawton 2000). However, observational methods in community palliative care whilst providing accounts which would otherwise go unrepresented in research findings (Griffiths et al. 2010) pose problems in regards to ethical approval, access and consent (Walshe et al. 2011). Therefore, whilst an observational approach may offer the chance to reveal how power/knowledge may work in different and more revealing ways, the problems with data collection experienced by other researchers suggests that for this project it may not be a suitable methodology. This makes it a somewhat high risk strategy for a neophyte researcher.

4.7.2 Interviews

Interviews are an established and theoretically interrogated method of data production in community palliative and supportive care research (Higginson et al. 1990; Grande 1996; Austin et al. 2000; Bolmsjö 2000; Grbich et al. 2001; Dean and McClement 2002; Andersson et al. 2008; McWilliam et al. 2008; Griggs 2010). There are three main ways that interviews can be conducted: structured, semi-structured, and unstructured interviews (Polit and Beck 2004).

Structured interviews use fixed questions (Polit and Beck 2004) and hence would be inappropriate both in relation to post-structuralism and palliative care research. Post-structuralism would suggest that to fix research questions in turn fixes research subjects and creates a regime of truth within the data production that is entirely controlled by academic discourses that participants have little to no access to; unlike other interview methods which may aim to use participants’ language during the interviews (Devault 1990).

Structured interviews if used to make statistical comparisons assume that the same questions will be understood in the same way and are therefore comparable (Edmonds et al. 2001; Osse et al. 2004). This runs contradictory to post-structuralist theory and also to this research question which focuses on exploring individual experiences. In addition to this there is also the risk of
using language which could cause upset and distress. Structured interviews are therefore inappropriate for this research project.

Open interviews have a topic which participants are informed of but there is no interview guide, only an emphasis on allowing participants to discuss whatever they feel should be within the interview (Polit and Beck 2004). Whilst such an approach is congruent with post-structuralism, it may at times make critiquing particular practices and extant literature in healthcare problematic by disallowing the researcher the ability to direct the interview towards pertinent topics. Therefore, whilst open interviewing techniques are drawn on for research projects which are not aiming to directly apply their findings, such as oral history. They are unsuitable for a project such as this which hopes in some way to produce results which can challenge and develop practice and policy.

Semi-structured interviews instead of using fixed questions have topic guides and therefore allow the interview to be continually restructured by interviewer and interviewee (Charmaz 2006). Post-structuralism would suggest that the words used and the meaning of words are constantly deferred and shifting and therefore there is an emphasis on asking participants to expand on their understanding of particular words and phrases (Baudrillard and Glaser 1994; Scheurich 1995).

In relation to this research question, semi-structured interviews allow a range of words and phrases to be drawn upon, even those used by the participants themselves, to reduce the risk of causing undue distress. Therefore, semi-structured interviews appear to be the most appropriate form of interview technique in relation to this research question and its theoretical underpinnings.

Even with open and semi-structured interviews, post-structuralism still understands interviewers as controlling the interviewee by virtue of the knowledge that they possess (Devault 1990). Sensitivity and subsequent acknowledgement by the researcher of the power relationships that this creates should result in participants being given opportunities to resist the power that shapes their answers produced in the interview. It is possible that if
an interviewee views themselves as always subordinate to the interviewer then they may just give answers that they think will ‘please’ the interviewer and hence merely repeat discourses rather than be critical of them. Therefore, consistent encouragement must be made to help participants feel validated in whatever views they may hold, encouraging them to be expressed and reassuring the confidentiality of any such responses. These factors must be acknowledged when analysing data and drawing conclusions for practice.

Repeated interviews have been demonstrated to allow the researcher to explore in more depth research themes and build up a relationship allowing more sensitive questions to be asked (Scholle et al. 1996; Charmaz 2006). However, within palliative care research participants are often unable to participate in longitudinal research due to high morbidity and mortality rates (Jordhoy et al. 1999). Therefore, second interviews need to be planned within weeks not months of initial interviews and a high attrition rate is to be expected.

4.7.3 Diaries

Whilst resolving the problems of context, power and researcher bias has been demonstrated as being intrinsically impossible, it is possible to use alternative methods of data collection to help moderate them. Several studies have used diaries to help to reduce the influences of: lack of time, domination by the researcher, and inaccuracy of retrospection (Zimmerman and Wieder 1977; Hughes and Callery 2004)

No literature has been identified directly examining post-structuralism in relation to diary research methods but many of the issues are similar to interviews in that the context of the data solicited by the researcher using a guide (appendix I) albeit broad. In this way the participant is guided to produce an intelligible account in relation to the research questions but because the interviewer is not present when the diary is being written it may be harder to account for how the researcher is affecting the data. However, if solicited in a way which encourages free thinking and writing it may produce data which
whilst constrained by the researcher to produce intelligible text, may be freer of the influence of the researcher than interviews. In addition diaries can be filled out much closer to the contact time of district nursing visits allowing different temporal perspectives to emerge.

4.7.4 Comparing diaries, interviews and observational methods

For this research project, whilst there are many methods of data production available, observational methods have been shown to be particularly problematic (Walshe et al. 2011) and further work needs to be done to establish how ethnographic work can be facilitated in community palliative care settings.

Therefore, interviews and diaries were chosen as the data production tools in this research project and are compared in table 4.1. Whilst it may be valid to give the diary before the first interview, it has been demonstrated that a personal relationship improves completion (Zimmerman and Wieder 1977). Therefore, the literature suggests that diaries should be solicited after the first interview for 7 days and instructed to record feelings on the what they feel gives them a sense of quality of care from their district nurse. This is in line with similar research (Zimmerman and Wieder 1977; Hughes and Callery 2004). Diaries can then be collected and analysed before the second interview to allow new themes to be explored in depth. Second interviews are therefore best approximately one month after the initial interview, this is mainly for pragmatic reasons in that after one month there is a greatly increased risk of patients dying before second interviews could take place (Jordhoy et al. 1999).

4.8 Data analysis

Analysis will draw from two main traditions, grounded theory for initial analysis and critical discourse analysis for theory generation. This is because whilst grounded theory has some well developed tools for analysis, even
Table 4.1 Diary/Interview comparison

<table>
<thead>
<tr>
<th>Method</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews</td>
<td>Can explore what the researcher feels is interesting; tailor interviews to particular need of the research question; contextual information can be noted in field notes (Murphy et al. 1998; Nunkoosing 2005).</td>
<td>Can be tiring for participants (especially in palliative care); skill is needed to negotiate boundaries; consent may need to be re-negotiated during interviews; retrospective so sometimes accounts could be vague or biased; can exclude patients who are unable to speak well; data collected is heavily influenced by the researcher; can take time to negotiate boundaries (Murphy et al. 1998, Nunkoosing 2005).</td>
</tr>
<tr>
<td>Diaries</td>
<td>Can be filled out immediately or close to phenomena of interest; completed at a time when patient feels able to or convenient; gives a voice to patients who are unable to speak well; is not as affected by the researcher (Zimmerman and Wieder 1977; Gibson 1995).</td>
<td>Entries can reduce at times of illness or distress (which are often particularly of interest to the study); researcher has less control over what data is elicited resulting in possibly irrelevant data; inaudible or illegible entries can result in lost data; all data may not be linguistic, pictures and diagrams may be used (Zimmerman and Wieder 1977; Gibson 1995).</td>
</tr>
</tbody>
</table>

Constructivist and postmodernist interpretations of grounded theory still hold to the idea of building theory from empirical data (Wuest and Merritt-Gray 2001; Clarke 2005; Charmaz 2006; Starks and Brown 2007) restricting the possibility of introducing post-structuralist analytical methods such as power/knowledge and dialectic formations of subjectivities. Discourse analysis, whilst well situated for analysing how and why representations are maintained does not
always have as open and clear methods as other qualitative analysis techniques (Burman and Parker 1993); especially so in relation to Butlerian theories (Scharff 2011). Therefore, the tools developed for the initial analysis of texts will be drawn from grounded theory with subsequent readings of the data occurring in line with discourse analytical techniques in line with the theoretical framework explicated in chapter 5.

4.8.1 Thematic analysis as observed in grounded theory

Charmaz (2006) suggests three types of coding, word by word, line by line and incident by incident. Word by word coding, whilst argued by Charmaz to provide a highly nuanced strategy appears to risk just converting participants words into researchers words. Whilst line by line coding seems to rely on the arbitrary division of word processing with different results possible depending on font size and margins. Therefore, both these strategies fail to be able to account for how the experiences of everyday life flow within a sea of discourses. Incident coding however, allows for the context of interviews to be captured in the codes; coding that which is performed as a discourse rather than just aiming to summarise a line of text in a theme. Therefore, if a discursive analysis is to proceed from coding, coding by incidents appears in general the most appropriate form of coding to work with. However, there may at times be key words and phrases that are desirable to maintain in the initial analysis and therefore on some occasions words and short phrases may be coded.

What coding is not aiming to achieve therefore is “remaining close to the social world” (Charmaz 2006: 54). Whilst it is important codes don’t misrepresent the data, nor should they be restrained by the discourses performed in the social world. Instead, a post-structuralist approach to incident coding should aim for codes that are justifiable but push at the boundaries of the social world by allowing codes that allow the data to be influenced by theoretical concepts.

In addition post-structuralist approaches to coding should avoid developing fixed coding structures which use either coding of previous interviews or extant
theory. Influenced by a Deleuzian understanding of knowledge production, Maclure (2010) argues for coding structures that appear rhizomatic instead of arborescent. In other words, coding should not follow a structure where there are clear levels and hierarchies with themes, and sub-themes. Instead coding should be non-hierarchical and allow for complexity to develop, allowing the linking of disparate codes with one another by resisting the desire to place codes in a hierarchy. Therefore, initial coding should be performed as freely and independently as possible from each data source. No naïve assumption is made with this statement that researchers can ‘bracelet’ themselves out for each and every analysis. Nor is it a call to not pursue interesting themes with subsequent participants; indeed, this is one of the key purposes of the coding process. Instead it is being argued that one should avoid privileging extant texts and coding structures, thereby allowing analysis to drive for heterogeneity rather than homogeneity allowing texts to exceed rather than be restrained by extant discourses.

4.8.2 Discourse analysis

Once this initial coding has taken place the themes derived can begin to be worked with discourse analysis techniques which aim to offer a way to “transform, rather than reproduce” (Burman and Parker 1993: 2) nursing research. There are however no hard and fast rules on how to undertake discourse analysis, to do so runs counter to its theoretical underpinnings of postmodernist and post-structuralist thinking (Burman and Parker 1993; Cheek 2004; O’Connor and Payne 2006; Starks and Brown 2007). Instead some broad questions have been put forward by O’Connor and Payne (2006) to stimulate and guide analysis:

- How have these particular discourses arisen?
- What versions of reality do they construct, make possible, and exclude?
- What competing discourses are available?
- Why have these discourses emerged now and what sustains them?
However, there are multiple forms of discourse analysis, all of which focus the above questions in different ways. As using Butler’s theories on morality is a novel approach to discourse analysis, it is useful to provide an example of how discourse analysis has been applied using other theories to help explain how Butler’s theories will be applied.

Jackson and Mazzei (2012) provide some of the clearest examples of how different theories can be applied to texts to provide different analyses, all of which are valuable, in some ways interlinked yet in other ways challenging to one another opening up rather than foreclosing analytical possibilities. In their study of first generation academic women they advocate the process of ‘plugging in’ different theorists. ‘Plugging in’ is itself a Deleuzian term from Thousand Plateaus (Deleuze and Guattari 1988) and in this sense is used to describe how no text can stand on its own and how instead all meaning is produced and functions in relation to other texts. Jackson and Mazzei then proceed to plug in six different but related theorists: Derrida, Spivak, Foucault, Butler, Deleuze and Barad. Their use of Foucault is presented here to demonstrate their discursive reading of power/knowledge in the interview of Cassandra, a first generation black university lecturer:

“[at] many events students challenged [my] knowledge… it was as if they felt I hadn’t even read the book, that I wouldn’t know the answer… some students have actually gone to my colleagues and told them what I said [in class] and asked them what they thought about it… most of the time they [my colleagues] would support me, but there would occasionally be sometimes that my colleagues would disagree with what I said, even though it was a topic where I was considered the expert, and they were not. I would never challenge their expertise in their area, but they would say ‘I don’t agree with that.’ And students would then feel that I obviously didn’t know what I was talking about because Dr. so and so didn’t agree with me… [when I moved to a different institution] I wrote a text book that has been received very well… the book is ten years old, but I still keep getting these cheques and so that has
opened up all kinds of doors for me… I’m the go-to person… I used to have a very low self-concept, but writing that academic book has help me feel less affected when a student challenges my expertise.” (Jackson and Mazzei 2012: 59 - 61)

Instead of coding to develop their analysis, Jackson and Mazzei read and re-read the texts with key questions around how power/knowledge (re)forms subjectivities and the effects that this has upon how Cassandra is able to form her subjectivity. A summation of their analysis is that earlier on in her career Cassandra felt less confident as an academic and was challenged on multiple levels. Her claims to knowledge were limited and in turn limited her claims to power. As academic prestige was gained, a new power/knowledge framework was set up where whilst the same incidents of questioning by her students occurred, her subjectivity shifted producing a different response to the challenges she faced. Importantly, the effects of power/knowledge are difficult to predict in advance, and it would appear that Cassandra did not write the book to shift her subjectivity. Therefore, cause and effect with regards to power/knowledge when read in a Foucauldian way become difficult to trace. Instead, what is analysed when reading a text are the possibilities that power/knowledge produces.

However, this is one ‘plugging in’ producing one reading. Readings may have equally employed a Butlerian reading to examine for how gender was operating through Cassandra’s performance as a black woman to make her a viable or unviable subject.

Therefore, discourse analysis in this thesis refers to the plugging in of interview data to the theoretical framework outlined in chapter 2; and discourse analysis needs to not only address the first four questions put forward by O’Connor and Payne (2006) but also needs to answer the ways in which discourses produce or preclude a becoming-other of subjective positions.
4.8.3 Use of qualitative analysis software

Whilst there is some scepticism in using qualitative data software (Stern and Covan 2001) this tends to be grounded in the assumption that it will be used to analyse the data rather than the researchers mind, and that it is typically complex to learn how to use it (Glaser 1998). The first of these objections has some limited logic in that analysis by a computer would result in analysis that relied on fixed algorithmic processes that were devoid of any human interpretation and were relatively meaningless. However, this is not an argument not to use such computer software, merely a comment on how to use it. The second objection appears to rely on the ability for any researcher to learn to use a particular software package. Whilst time could be better spent doing research rather than learning how to use a particular qualitative analysis software package (Glaser 1998), surely the same argument could be put forward for word processing packages. This argument also doesn’t take into account the time that can be saved and the additional security afforded by qualitative data analysis software enabling encryption and backing up of electronic files. However, to use or not to use qualitative data analysis software need not be set up as binary. Instead it may at times be productive to revert to traditional methods of pens, paper, scissors and notebooks. Therefore, in conclusion, it appears more of a personal choice whether electronic software is used to facilitate data analysis. In this research study there was funding to attend a two day workshop to learn how to use NVivo. This was attended: a two day course did not seem an onerous amount of time to spend learning how to use such a piece of software. Therefore, for this study, NVivo was chosen to facilitate data analysis with the occasional use of pens, papers and scissors to aid data analysis.

4.8.4 Combining thematic analysis with discourse analysis

The combination of thematic analysis as observed in methods such as grounded theory with discourse analysis using critical theory is not a straightforward nor contentious one. Both advocates of each methodology
reject the other. However, if the right elements are chosen, then it is possible to understand how they can be productive and stay true to post-structuralist aims of multiplying analytical possibilities.

Without the thematic analysis approach it would have been difficult to develop research questions that remained intelligible to the research subjects. Jackson and Mazzei (2012) reject thematic analysis, but in a research context where participants (arts and humanities lecturers at liberal American Universities) are well versed in complex and abstract theoretical ideas. Therefore, developing interview questions in direct reference to these theoretical ideas would be less problematic than when interviewing those who are naïve to post-structuralist theories. In their research there is also no clear way of developing interview questions that go beyond the mind of the researcher and/or post-structuralist theory. If no thematic coding occurs, then adding topics to an interview protocol that the participants have repeatedly raised, warranting their further investigation, becomes problematic. This may be justifiable in the research project that Jackson and Mazzei undertook as its aims were to demonstrate a methodology rather than deeply investigate a topic area, but this methodological flaw in discourse analysis techniques cannot be ignored. Therefore, combining thematic analysis in the form of qualitative coding as observed in grounded theory allows interview questions to change and develop, facilitating findings that may address what is important to those being researched. However, this in turn must be balanced by allowing research questions to be influence by theory to open up the extant social world to challenge.

When bringing these two methods into NVivo it becomes possible to not only plug in individual transcripts to the theoretical framework, but also plug in transcripts to one another and other data sources via thematic coding. This allows productive excerpts of transcripts to pull on similar excerpts from other transcripts greatly multiplying the number of connections and analytical possibilities in the data and hence is in keeping with a post-structuralist philosophy towards analysis.
Analysis therefore takes the themes derived from the initial coding and aims to question them not only in relation to themselves, as may happen within grounded theory analysis following a constant comparative method, but also in relation to the theoretical ideas laid out in chapter two.

Once this process of discourse analysis has been undertaken the results can be put into a relationship with current healthcare policy and practice. Whilst discourse analysis’ use of abstract theories has lead to it being questioned for its utility in practical disciplines (O’Connor and Payne 2006). It is in fact discourse analysis coupled with abstract theory which provides its strength, as Maclure puts it:

“The value of theory lies in its power to get in the way: to offend and interrupt. We need theory to block the reproduction of the bleeding obvious, and thereby, hopefully, open new possibilities for thinking and doing.” (MacLure 2010: 277)

Within the philosophical underpinnings laid out in chapter two, theory can be understood as not only enabling the production of novel and challenging analyses, but also answering the moral imperative of post-structuralism to allow new subjective positions to be opened up and inhabited.

4.9 Rigour and validity in post-structuralist research

Once research has been assessed as being basically logical (i.e. free from contradictory statements), ways of ensuring validity and rigour in qualitative research are many and varied and include methods such as peer debriefing, peer checking and triangulation of methods (Polit and Beck 2004). Yet rigour and validity are two concepts that remain under-theorised by post-structuralist researchers, to the extent where Clarke’s (2005) entire text book putting forward an alternative form of postmodern grounded theory fails to account in any way for either of the terms. The paucity of considering both these terms seems to be their mimetic link to concepts such as truth which post-structuralism has worked hard to remove from its vocabulary. Whilst authors
like Rolfe (2006) recognise the need not to completely remove this from the vocabulary of research, they fail to recognise their necessity in producing the researcher as a viable being. If within the social world of research the concepts rigour and validity produce research, then they must come to form the researcher themselves. Therefore, to attempt to escape (or ignore) the terms all together risks becoming an invalid researcher. Instead, what must be attempted is an exceeding of the terms rigour and validity reforming them within a post-structuralist framework.

Rigour and validity in post-structuralism must not claim to have produced an overriding truth which is more believable than any other truth. To do so would automatically invalidate it as post-structuralist research by privileging one set of knowledge over another (Rolfe 2006). However, there must be some way of assessing what research should be paid more attention to than another without relying on tools to measure the truth of one against another. Therefore, instead of the level of truth that a piece of research can claim as being a measure of rigour and validity, what should be assessed is how the research multiplies the possibilities for alternative truths to be recognised and multiply the possibilities of academic and policy discursive positions. However, this must not be done in a way which tries to replace one truth with another claiming some form of emancipatory effect for the subjects of the research (Lather 1993). This would merely be a thinly veiled form of paternalism. Instead multiplications of subjectivities must occur for rigour and validity to be recognised in post-structuralist research, just as with subjects positions being made viable through power/knowledge restricting subjectivity, so validity and rigour become viable when their limits are declared and recognised.

Therefore, for research to be considered rigorous and valid there must be: a comprehensive accounting for the limitations of research; and a demonstration of how it multiplies rather than restricts subjective possibilities.
Chapter 5

Methods: How the study was conducted

5.1 Introduction

This chapter will examine how this exploratory qualitative interview study was conducted. It uses the first person as it relates directly to the process undertaken by myself (the researcher) and how I applied, critiqued and developed the chosen research methodologies explicated in the previous chapter whilst keeping true to the post-structuralist underpinnings in chapter 2.

During the planning of this study a decision was made to recruit through a variety of primary care nurses: District nurses, community matrons, and specialist nurses (such as heart failure nurses). This was because when discussing my plans with other academics it became apparent that several recent studies had struggled to recruit sufficient numbers when recruiting only via district nurses. It was also hoped that if non-cancer specialist nurses were approached to recruit it would provide more chance of recruiting non-cancer patients into a palliative care study.

The initial research setting was two primary care trusts. This was mainly for pragmatic reasons. Whilst it was known at beginning of the study, again through discussion with other academics, that further research sites may need to be added to achieve the desired recruitment, it was recognised that organising and meeting with staff from more than two primary care trusts in the initial few months would be impractical. Over the course of the study when it became apparent that recruitment would not be achieved through only two primary care trusts, recruitment was expanded to five primary care trusts (two of which were applied for concurrently with hospices) and four hospices.
5.2 Study approval processes

Before any research could be conducted it was necessary to get research portfolio, ethical, and research and development approvals via the Integrated Research Application System (IRAS).

5.2.1 Portfolio approval

Application was made to the cancer research network portfolio via the IRAS system. This was done to give me access to additional support for my study. This support was twofold, firstly from research nurses employed by a variety of organisations to facilitate recruitment onto research studies that were adopted onto the research portfolio. Secondly, when adding additional NHS sites, portfolio support staff took on the role of liaising with local research and development (R&D) staff utilising a centralised document store greatly reducing the amount of contact that I had to have with R&D departments to one signature at the end of the process.

5.2.2 Initial selection of research sites

Conducting research through NHS organisations meant that there was a limited choice in which primary care trusts could be approached. For example if similar research studies were under way, or if key managers were on long-term sick, then approaching these sites for approval would prove futile. Equally, because of budgetary and time constraints interviewees had to be relatively nearby (within an approximate 75 mile radius from the University of Manchester). Once these factors had been established two local primary care trusts were approach in July 2010 (prior to ethical approval). Both agreed to take part in the study once ethical approval was established.

5.2.3 Research ethics approval

Whilst this was a long process (six months from beginning to fill in the form to gaining approval), it is essential to any research project involving human participants. Although lengthy, in retrospect it is clear how the process
encourages researchers to consider in detail the core components to any research ethics application.

From the outset the information sheets (appendices D and E) were key components in the study and to this end a research advisory group (RAG) consisting of patients, carers, district nurses and academics was convened to help develop the information sheets. This allowed issues around wording and presentation of the recruitment pack to be openly discussed with patients who had a life limiting condition. When questioned by the REC about whether terms such as “palliative and supportive care” and “severe or life limiting” were likely to cause distress we were able to reassure them that a group of patients had already discussed this and felt that it was the most honest yet clear phrasing to use in this research project. Once NHS research ethics approval was granted (reference 10/H1013/3), University research ethics was applied for and gained shortly afterwards.

5.2.4 Hospice approval
Two hospices (A and B) were approached unsolicited, hospice C, hospice D and hospice E approached me through the research portfolio. Whilst gaining approval from NHS organisations was bureaucratic, it was generally standardised and once approval had been gained from one NHS trust, adding additional trusts (presuming there was capacity to conduct the research) was simple. The same was not true of hospices who are outside of the IRAS approval process and instead all had different requirements. These requirements were met on an individual basis and all but one hospice agreed to take part in the study.

5.2.5 Consent
As part of the approval process it was necessary to demonstrate that the research process would be free from any coercion and that informed consent was able to take place. Therefore, this research study put in place a reply slip system (appendix F) inside the information pack thereby allowing potential participants time away from the recruiter to consider their participation. Whilst
healthcare professionals were asked to hand out packs, it was made clear that participants were not to be ‘chased’ for responses. An independent point of contact was also included on the information sheets (appendices G [patient] and H [carer]).

5.2.6 Sample size

Whilst sample size was not set *a priori* in order for the study to be approved it was necessary to give an indication of the anticipated sample size. Similar studies where reviewed (Beaver et al. 2000; Kirk et al. 2005; Griffiths et al. 2007) and it was noted that a sample size of approximately 30 patients and 30 carers would be likely to be sufficient. Therefore, for ethics and research and development approval purposes a sample of 40 patients and 40 carers was requested to avoid having to re-apply for an increase.

5.3 Recruitment and sampling

Once approval for the study had been granted and the initial research sites (PCT A and B) and been approved, recruitment and sampling could begin.

5.3.1 Recruitment strategy

Recruitment initially involved arranging face to face meetings with every recruiting healthcare professional to explain the study and ask them to hand out recruitment packs to potential participants. Success at contacting and maintaining contact with healthcare professionals varied with PCT B proving particularly problematic. Inclusion and exclusion criteria for handing out recruitment packs were:

Patient inclusion criteria:

- Patients who are receiving or requiring palliative or supportive care, or who have a severe life limiting disease as determined by their healthcare professional.
- Over 18 years old.
- Considered ‘active’ on the case load by district nurses case.
- Considered able to give consent by their healthcare professional.
- Considered able to participate in an in-depth interview by their healthcare professional or keep a diary (audio or written) after a shorter interview.

Carer inclusion criteria:
- All adult (over 18) carers.
- Considered a 'carer' by the patient.
- Able to consent.
- Able to participate in an in-depth interview or keep a diary (audio or written) after a shorter interview.

Patient Exclusion criteria:
- Patients who are not receiving or requiring palliative or supportive care, or don’t have a severe life limiting disease.
- Not active on a district nursing case load.
- Patients judged unable to consent by their healthcare professional.
- Current contact with chief investigator as a patient.
- Resident in a nursing or residential home.

Carer exclusion criteria:
- Professional care staff of the patient.

Whilst it was hoped that theoretical sampling would further develop these original inclusion and exclusion criteria to allow participants to be chosen for their ability to provide richer data on certain aspects, this did not occur. Instead theoretical sampling aimed to direct recruitment efforts towards particular demographic and diagnostic characteristics. Figure 5.1 details recruitment with its multiple strategies.
Recruitment proved successful for the purposes of this study, but at times took up an exceptional amount of time building and maintaining contacts and involved expanding beyond the original plan (phase 1). One of the key problems necessitating expansion beyond phase 1 was staff turnover, particularly managerial turnover. This resulted in it being extremely difficult to ensure that healthcare professionals were aware of the study and informed about whom to hand recruitment packs to. For example, in PCT B (who only recruited one participant) from July 2010 to September 2011 there were three different managers for district nursing services. There was also a high turnover in all PCTs of charge nurses for district nursing teams. Again, this was particularly problematic in PCT B where six out of the seven teams changed charge nurses between September 2010 and September 2011. This meant that recruitment for research projects simply did not occur without meeting again with the new charge nurse, who often would often only have a very short time to meet with me. When the fourth charge nurse in PCT B changed, in view that only one patient had been recruited from this PCT, a decision was made to focus recruitment efforts on the more successful sites. Because of the difficulties experienced with PCT B with recruiting, in November 2011 a decision was made to add PCT C and approach hospice daycare centres to recruit using research nurses (phase 2). This proved much more successful. However, in May 2012 it was felt that the majority of eligible participants had been approached and an offer was received from Hospice E to further aid recruitment, this became phase 3. PCTs D and E were added to complement hospice sites where recruiters were also NHS employees and therefore required NHS R&D approval from their employing trust. District nursing teams were not approached for these sites.
**Figure 5.1** Recruitment strategy phrases

**Phase 1: September 2010**
- PCT A
  - District Nurses N= 3 of 24*
  - MacMillan Nurses N= 1 of 4

**Phase 2: November 2010**
- PCT C
  - Community Matrons N= 0 of 0*
  - Specialist Nurses N= 0 of 0*
- District Nurses N= 3 of 13*
- PCT D
  - Specialist Nurses N= 0 of 0
  - Specialist Nurses N= 0 of 0

**Phase 3: June 2011**
- Hospice E
- PCT E
  - NHS Research nurse N= 2 of 4

**Key:**
- = participants recruitment occurred
- = no participants recruited

N = a of b indicates number of participants recruited (a) versus number of recruitment packs handed out (b)

* Indicates approximate figure
5.3.2 Research nurses

Research nurses were a particularly effective way around the problem of recruiting with community healthcare professionals. However, they only appeared to be able to work within geographically contained spaces such as hospice day care centres. Community healthcare professionals repeatedly declined research nurses direct access to patients in the community. For example, healthcare professionals always wished to make the initial approach face to face with potential participants, even when they may not be meeting with them for several weeks or months. Whilst healthcare managers were willing to allow research nurses to approach patients, district nurses were unwilling to make telephone contact (to ask consent for research nurses to contact potential participants) or allow research nurse to make initial approaches. Therefore, healthcare professionals insisting on making face to face approaches about a research nurse discussing a research study only complicated matters, when information packs had already been designed to serve the purpose of explaining the study. This rendered research nurses in a community setting futile. However, research nurses functioned in a completely different way when working within a hospice day care centre where staff, patient and research nurse were all close enough for contact to be initiated quickly and easily. It is possible that with the research nurse working in day care centres alongside hospice staff that the staff there felt more in control of situations and able to monitor an unknown professional more closely. The other possible reason why research nurses worked far better in a hospice setting was the ease at which hospice day care staff felt discussing palliative and supportive care. This is in stark contrast to the district nurses and community nurses who often recounted potential participants where they were unsure whether they knew their diagnosis and prognosis and were therefore reticent about handing a research study pack to them. Whatever explanations may be offered, without research nurses and hospices working on this study, recruitment would have been significantly more difficult and unlikely to have been as successful.
5.3.3 Recruitment packs

Recruitment packs contained either the patient (appendix D) or carer (appendix E) information leaflets, reply slips (appendix F) and a pre-paid envelope. Exact numbers of recruitment packs handed out to potential participants was at times difficult to establish because of the afore mentioned staff turnover. Despite always keeping a record of how many packs were given to different recruiters, packs were often lost, phone calls went unreturned or just general uncertainty whether three or four packs had been given out. Where this is the case an asterisk is placed next to the second figure in figure 5.1.

**Figure 5.2** Number of participants approached versus number of participants recruited

As can be seen in figure 5.2 approximately 75 packs were handed out resulting in 26 cases being recruited, just over a 1 in 3 rate, similar to other community healthcare research projects (Miller et al. 2003). Reinforcing the idea already established in the literature that people may wish to take part in palliative and supportive care research studies as much as in other areas of research and that healthcare professionals prevent potential participants from
taking part in research which they may wish to participate in (Ewing et al. 2004). Figure 5.2 also shows that four additional cases responded but were unable to be interviewed. One, after sending the reply slip became unwell and died in hospital. Two on arrival to the house were too unwell. One declined the day before the interview, feeling too unwell and decided after two follow up phone calls (made at his request) at weekly intervals he no longer felt well enough to take part in a research project. Only one patient was refused, whilst he had heart failure (a potentially palliative illness), he did not consider it ‘palliative’ heart failure, nor was he receiving care for it from his district nurses. He had only received care from his district nurse for dressings after having a pacemaker fitted nine months prior to receiving details about the study. Therefore, because of the lack of perceived palliative needs, and the lack of contact he had with his district nurse, his participation in the study was mutually declined. Demographic or any other details were not collected for any of these potential participants.

5.4 Data production

5.4.1 Adapting data production methods

Chapter four discussed the benefits of having two interviews with intervening diaries. Therefore, it was planned in this research study to follow an interview-diary-interview method. Whilst it was recognised in the planning stages that this might be problematic due to participants becoming too unwell it was not anticipated that it would be entirely unsuccessful. Only three cases contained second interviews (P12, P7, P6): seventeen declined due to worsening health meaning that they felt a second interview would be burdensome for little extra benefit to the research; four didn’t respond to telephone calls for a second interview; and in two cases the patient had died one month prior to follow up. In the cases where patients had died I asked my condolences to be passed on via the healthcare professional and that it would be inappropriate for me to interview the bereaved carer so soon after their bereavement.
In addition to the lack of second interviews diaries also proved problematic. Whilst literature and theory suggested that diaries offered a valuable alternative data collection tool, after the first eight cases either declined or failed to complete diaries it was decided to change the way that they were offered. Instead of being ‘part’ of the research process, diaries were instead highlighted as an alternative for participants who may only be able to undertake a short interview, but still wished to contribute to the research. Whilst in the end no participants made use of diaries, there were at least two participants who were offered to take part in the research who had motor-neurone disease and parkinsonism who were unable to be interviewed for longer than 10-15 minutes but were physically able to keep written and or audio diaries. Whilst both participants subsequently decided not to take part in the research project it was not because it was inaccessible on a practical level.

Therefore, this research study became a purely interview based study, with only three cases being interviewed twice.

5.4.2 Interviewing

How to interview

Whilst an interview protocol was designed with the RAG with sample questions (appendix B) it was clear that to remain an ethically sound study questions would be phrased and broached initially using broad open ended questions and then progressing with language that reflected how the participants spoke to me. For example, if a participant used the word “death” or “dying” I would reflect those words back to participants when phrasing questions about district nursing care. However, if not, then I would ask questions about “the future” which could be interpreted in a number of ways and avoid distress. Whilst a few participants became tearful, particularly when discussing their diagnosis and ‘the future’, none appeared to become distressed to the point where additional help was required. In all these circumstances it was checked that they were happy to continue with the interview and in all cases participants were. Only one case P8, appeared to be in denial about her diagnosis and
prognosis. This resulted in an inability for me to really address any issues at all around her district nursing care in relation to palliative and supportive care. When asking about the future she felt unwell and at this point, at my discretion the interview was stopped.

*Interview characteristics*

The mean length of first interviews was sixty three minutes, ranging from twelve minutes to one hundred and nine. Second interviews were slightly shorter at fifty seven minutes, ranging from forty to sixty nine minutes. Three interviews were jointly conducted between patient and carer (P6/C6, P16/C16, P25/C25) this was mainly for practical reasons as to conduct them otherwise would have necessitated the patient and carer to sit or rest somewhere impractical and uncomfortable. One interview P20, had a friend present in the room most of the time and was open and honest that she felt safer with a stranger in her home to have a friend present at the same time. Whilst doing joint interviews will have changed what was said within the interview itself, generally patient and carer both spoke equally. In all three joint interviews and P20, diagnosis and prognosis was openly acknowledged. Therefore, instead of restricting what could be said, at times it helped spark ideas between participants in much the same way that might occur in a focus group.

All second interviews were conducted between four and eight weeks after the first interview. Second interviews mainly served to help develop and deepen themes such as discussion on information sheets. Also, discussion around potentially more emotive topics such as end of life care were easier to undertake because there was a clearer understanding of what patients and carers were willing to talk about and I had been able to reflect on the initial interview.

Only thirteen carers were interviewed for this research study. Two patients had no lay carer who could be interviewed and relied entirely upon professional services for their care. The other fifteen carers declined to be interviewed either explicitly or implicitly through non-response.
All interviews were audio recorded. Generally once social greetings had taken place I sought to gain consent as soon as possible to facilitate audio-recording and to capture data that can otherwise be lost about social situations. Starting the recording early also meant that by the time the more focussed interview questions began participants appeared to notice the recorder less.

Where and when to interview
One participant (C3) was interviewed at the University and had his travel costs reimbursed and four participants were interviewed in a private room at their hospice daycare centre. The remainder were all interviewed in their homes. The variety in settings only seemed to overly affect the content of interviews in the case of C3 where I felt that he was discussing issues with me that he may have felt were difficult to discuss in his home, when he and his wife were struggling to come to terms with and communicate about her life limiting illness. For all participants, it felt important for them to choose where they wanted to be interviewed to ensure that they felt most comfortable. Reasons given for interviewing away from the home often centred around the home being a busy place with lots of visitors who would interrupt the interview process. One participant in particular (P9) welcomed the opportunity to be interviewed whilst he was an inpatient at a hospice for the night for a blood transfusion citing that it would keep him company for what was otherwise for him a quite boring procedure. Because I was not associated professionally with any of the research settings (apart from C3s interview at the University), the balance of power and the subsequent data collected between the researcher and participant seemed unaffected by the variety of venues.

The researcher's role
Within a post-structuralist framework, I began to understand that who I am as a researcher will inevitably influence the data that I am offered from participants by dialectically forming who the participants are and can be. When introducing myself to participants I discussed my role as a researcher and that the project was part of a PhD (both facts that were on the participant information sheets). As interviews developed I aimed to always be open about
myself, my background as a nurse, and my personal life if asked. Never did I feel my personal safety was at risk with me being honest about issues such as politics, sexuality, or class. In fact, quite the opposite at times occurred where participants engaged in discussions of what I considered deeply personal in nature, occasionally citing that I was the first person they had spoken to about various topics. At times this was directly pertinent to the research question and at other times not so. However, allowing participants to become more than just subjects of myself and the discourse of nursing research at times gave a sense that conversations around death and dying and other emotive topics were allowed to happen because a quasi-friendship (even if just within that one interview) had been allowed to develop. Within this framework of allowing the relationship to develop, for my own protection I was always clear that my involvement would not go beyond the research project.

Whilst my role as a researcher was not akin to my previous role as a practicing palliative care nurse, I still felt compelled to act if concerned clinically and contact relevant professionals. Only one such case (P3) arose. After the interview I reflected with one of my supervisors about my concerns and concluded that I could not allow potential harm to occur to someone if I felt that it could be addressed. Knowing from the interview that she was not due another visit from any healthcare professional for another 6 days I contacted P3 the subsequent day and spoke to her and her husband (C3) discussing that I felt that if the drowsiness she was experiencing was bothersome she could contact one of her healthcare professionals for reassessment. Not knowing anything about their case I was careful not to ‘interfere’ and offer specific advice around which medications it might be, being honest about my reticence to offer such advice. Instead, I suggested that they give my office number to their GP or district nurse if they wished to contact me. P3 and C3 were both happy with this.
5.5 Data organisation and management

This research project complied with the necessary guidelines from the data protection act and Caldicott principles (Department of Health 2005b) maintaining the confidentiality of participants. Recordings and transcripts of interviews were kept securely in a locked storage unit, and digital information was stored on an encrypted laptop with data backed up onto a secure server. A coding system was used to identify participants stored in a different secure location to consent forms and interview transcripts. There were no cases where confidentiality needed to be broken for a participant's or my safety. At the end of the project all data and coding systems will be destroyed after five years.

All interviews were audio taped and transcribed by a professional transcription company. Confidentiality agreements were agreed for this process (appendix M). On receipt of the transcripts from the company they were checked in tandem with the recording for accuracy. Without exception the meaning of the transcribed text was congruent with the audio. There were some minor errors in relation to misspelling of proper nouns, and very occasional grammatical and other spelling errors. However, it was not uncommon for a transcript to go unaltered.

All data was entered into NVivo 8 for data management and analysis; the strengths of being able to quickly and easily re-edit codes and keep a safe, secure, and multiple backups of my work was immensely reassuring. Analytically it also facilitated comparing disparate data with my interview data such as video, audio and other textual representations of district nursing. Whilst this set of data will not prominently feature in this thesis, being able to analyse widely different types of data in one software package helped link and develop the ideas in this thesis.
5.6 Data Analysis

As discussed in chapter 4 two forms of data analysis were employed in this thesis: thematic analysis, influenced by grounded theory to develop the interview protocol and themes within the research; and discourse analysis, influenced mainly by Butler’s theories on morality to provide a novel reading of quality palliative and supportive district nursing care.

In keeping with the post-structuralist idea of multiplying possibilities, thematic analysis on transcripts happened as independently as possible not aiming to build a coding scheme from one interview to another. Initial coding aimed neither to abstract too far from the words used by participants nor code in keeping with extant transcripts. Initial coding served to develop the interview protocol and to condense complexity so texts could eventually be brought into an analytical relationship with each other without precluding too many analytical possibilities. An example of how initial coding occurred for P16 and C16s joint interview can be observed in appendix N where there was a total of 221 different codes. Appendix O shows how many codes were present in each interview, ranging from 70 to 426 with a mean of 178. Joint interviews and longer interviews generally contained more codes.

5.6.1 Developing interview protocols
Once the initial coding was done for interviews, thematic analysis began to help to develop the interview protocol and provide manageable themes to work with discourse analysis techniques. Whilst effort was made to always perform initial coding before the next participant was interviewed. This was not always practicable in a palliative care study because delaying by even just one or two days may have meant loosing participants to death or ill health. Therefore, interviewing rather than coding had to take priority. Examples are given in appendices V and W of the coding structures from interviews with P3 and P16 respectively. Comparing these two coding structures it can be observed that there are some common codes. For example ‘timekeeping’ reflected the question in the initial interview protocol (appendix B) and hence, often got
coded in a similar way across all interviews. However, there are also a wide variety of codes which are not reflected across other interviews. No aim was made to make codes fit into a formal structure. However, it can be observed that P16 has less complexity than P3s coding structure. This reflects the inability of myself as a researcher to 'bracket out' all extant coding when coding other transcripts, which within a post-structuralist approach to research is not expected, but instead must be accounted for and recognised. Despite this it can be seen that even P16s coding still retained some unique features such as the code 'lack of consumerist thought' therefore retaining new analytical possibilities.

Informal revision of the protocol was constant. When previous interviews and theory came to mind whilst interviewing, notes were made on the protocol and at appropriate points additional questions were asked that were not on the protocol. However, in order to develop the research question protocol it was necessary to formally review previous transcripts and perform some form of thematic analysis. In a similar way to coding this was also a pragmatic exercise where interviewing had to take priority over formally reviewing and refining the interview protocol. Therefore the protocol was formally revised after P6’s interview and P18’s interview. For example, when reviewing the protocol after P6’s interview ‘knowledge’ was something that was mentioned in the interviews of P1, C1, P6, C6 in a variety of ways, either about their extant knowledge of district nursing services and/or knowledge that they had of their current district nursing service. Combining this with the theoretical framework it became appropriate to add a section about knowledge.

5.6.2 Developing themes for analysis
As these themes in the interviews continued to emerge they were gradually collected in NVivo. The themes changed and developed over time and the final structure can be seen in appendix Q. The three final ‘core’ themes of busyness, knowledge and the home were decided upon for three different but interlocking reasons: that they had significant and wide ranging effects on the morality of district nursing practice. In line with post-structural theory effort was
made wherever possible to allow variety and difference in the data when coding. Even though this inevitably fails due to human fallibility, the preservation of ‘sub-themes’ and their utilisation wherever possible in relation to the ‘core themes’ helped to develop an analysis that allowed the linking (but not a comparison to try and create homogeneity as in grounded theory) of disparate themes. This provides a novel analysis which resists using the extant social world as a basis for theorisation (as in grounded theory methodologies), but still utilises the coding tools in grounded theory to manage a large amount of data. Whilst the three core themes all had in common a wide ranging effect on the morality of district nursing practice, they arose within the analytical process in subtly different ways.

**Busyness**
The coding structure for the theme ‘busyness’ can be seen in appendix R. The word ‘busy’ and its conjugations were noted to be present in 17 out of 31 participants’ interviews (see appendix S for the memo where this was noted). This alone was not enough to make it the subject of an entire chapter, but it was enough to examine how it affected and interacted with other themes. An example of this analysis in a diagram format can be seen in appendix T where the effect of busyness on patients’ conceptions of timekeeping was noted and a memo written (appendix U). When it became clear that ‘busyness’ had the potential to affect a wide range of other themes, codes and interviews where the phrase ‘busy’ occurred were reviewed for the effects of busyness. These were then gathered into a sub-theme ‘effects of busyness’ and a memo written (appendix V). The writing of this memo made it apparent that ‘busyness’ had the potential to affect a wide range of district nurses actions and these ideas were then developed in line with discourse analysis techniques to read the morality of the ways in which busyness operated.

**Knowledge**
Knowledge as already discussed came up early on in the interview process. It would be false to suggest that this occurred in the same way as the theme ‘busyness’, as ‘busyness’ at the time of data collection was not related in my mind to any broader social theories. However, knowledge was related to the
theoretical ideas of Foucault and Butler, both of which were being read prior to, during and after data production. Therefore, when patients and carers began to mention the word ‘knowledge’ there was an instant resonance with the theoretical framework of post-structuralism and this was quickly picked up on and integrated into the interview protocol. Theoretical ideas from Foucauldian theory then began to direct questioning and subsequent coding such as:

“Interviewer: Right, okay. So did you ever get any information?

P3: No.

Interviewer: Nothing written or…?

P3: No.”

This line of questioning specifically referenced Foucauldian ideas (Foucault 1973) of how the distribution of knowledge affected the power/knowledge that medical professionals had. When analysis progressed to examine the effects of knowledge, in a similar way to busyness it was noted that it had wide ranging effects on morality of district nursing care.

The home
The theme pertaining to the home is directly related to Joan Liaschenko’s (1994, 1996) work which was purely theoretical without any empirical evidence to confirm or refute her ideas. Though she has since expanded on these ideas with empirical data in intensive care settings (Liaschenko et al. 2011), no work has taken her ideas and integrated them with empirical data in relation to the home. Therefore, questions around the home were asked throughout the data production (reflected in the codes in P3’s and P16’s coding). It was decided to make this a core theme when all these comments on the home were collected together, and the potential for post-structural theory and the empirical data provided a particularly challenging analysis that produced many useful questions whilst developing theorisation of district nursing in the home.
Sub-themes

Whilst labelled ‘sub themes’ in the final NVivo coding, this isn’t to suggest some kind of hierarchy in the analysis, instead these themes were developed in a similar way to the above ‘core themes’ using thematic analysis or extant theory. They did not however present the same potential to widely influence district nursing care. These themes included: time and timekeeping, future care, relationship, limits of district nursing care, psychosocial care and chatting, affective economy of district nursing (becoming young), extant discourses on district nursing, previous district nurse experience, district nurse performances collected, district nurse performances thematic, patient performative concepts, district nurse becoming, genesis, information leaflet. These themes served best to help demonstrate the ways in which the three core themes operated on a moral level. It is not to say that ‘time keeping’ does not have an effect on ‘psychosocial care and chatting’ and many other themes (post-structural forms of analysis almost dictate that there must be some connections and some effect). However, ultimately decisions had to be made about which themes to present in this thesis. Therefore, the ones that operated in the most novel, morally influential and academically challenging ways were chosen.

Exemplar of core themes omitted from final analysis

A detailed analysis was conducted of media representations of district nursing covering national newspapers, television and radio. Elements of this analysis can be seen in the coding for busyness under ‘media representations of busyness’ (appendix R). The theme was developed due to P3’s (see appendix W for coding structure) and C10’s discussions around how media had influenced their conceptions of district nursing and the sources that they cited, along with others were analysed. A draft analysis of the gathered data from various media analyses and interviews was conducted. However, it was felt that whilst this was an interesting topic to write on, the moral implications of media representations were not as extensive and as pervasive as discourses such as ‘busyness’ and ‘knowledge’. Whilst the media served to frame initial ideas around district nurses it did not continue to restrict patients and carers subjectivities in the same way that other discourses did. Therefore, it was
omitted for detailed analysis in this thesis and treated in the same way as the other ‘sub-themes’ from the interview data.

5.6.3 Data analysis – discourse analysis: the reading of morality

In chapter 4 it was explored how different theoretical frameworks could influence discourse analysis techniques, how one text plugged into another to create meaning. An example is given here of how once the data had been organised from 35 different participants into a broad range of disparate themes it became possible to examine and link the transcripts via the loose coding structure and begin to plug these themes into chapter two’s understanding of morality. The example of busyness as expressed in P16s interview (appendix X for coding structure and appendix N for excerpt of coding of interview transcripts) is used to demonstrate how this process of plugging in can occur with one text and then be further facilitated to plug into other texts via the coding structure to expand and develop a reading of busyness across a wide range of texts. Reading just this example of busyness alone only demonstrates one way in which busyness operates: as a way to legitimise nurses (and other healthcare professionals) not chatting and only performing biomedical care tasks; and as an extant discourse that is used to form subjectivities.

However, when the various themes of busyness were collected together, as can be seen in appendix R, the wide ranging of effects of busyness could be observed and texts linked together to read the ways in which busyness operated on a moral level across different cases. Whilst it is possible that a small number of texts could be linked ‘in the researchers mind’ in a similar way to the way that they are in NVivo when performing a discourse analysis; linking would become increasingly difficult across a wide range of texts and data sources as used in this study. Therefore, coding and thematic analysis facilitated by NVivo functions to facilitate the plugging in of one set of coding to another set of coding. The codes themselves are not used for analysis, but instead facilitate ways into the data. Because there was such diversity in the coding, the tenets of a post-structuralist analysis remain intact by virtue of
there being a vast number of ways to link texts together via disparate coding structures.

5.6.4 Data saturation

As explicated in chapter 4, saturation was not searched for in a traditional sense where themes become stable, instead saturation is considered to occur when themes appeared to be stable and the reasons why these themes appeared stable had been established. In this way, themes around extant discourses on district nurses quickly reached saturation as nearly all patients and carers described district nurses as being concerned with dressings and injections. However, what was not apparent was how and why this stability occurred. In order to understand this stability, further questions were asked during interviews to try and establish how and where participants gained these understandings from and what resources were available to them to develop and change their knowledge of district nurses.

Saturation was not felt to have occurred with one of the last themes emerging around the possible development of an information leaflet. This was partly because it began to emerge as a theme in the third to last interview. However, because this theme started to investigate more than the implications of the initial research question, it forms more the basis for a future research project rather than part of this research project. Time and resources also played a part in this decision in that this theme only began emerging in August and September 2011. When data collection was aimed to last approximately one year finishing in September 2011 it was felt spending additional time would not benefit the original research question and instead may reduce time for analysis and writing up. Therefore, whilst it is a valuable theme which may help direct future research, it was felt that as saturation had occurred in all other themes data collection could cease.
5.7 Rigour and validity

As discussed in the previous chapter, rigour and validity in post-structuralism are at best slippery terms, and at worst just ignored; yet they cannot be allowed to slip away as demonstrating rigour and validity performs my viability as a researcher.

Post-structuralism is clear that rules and structures cannot be followed, therefore I am unable to demonstrate rigour and validity by virtue of following a set of pre-ordained rules for qualitative analysis. In fact, post-structuralism posits the exact opposite, that wherever possible rules should be challenged to create new lines of flight, new ways of doing, away from the trappings of power/knowledge. This does not however mean that no rules were used (rules create viability, there must be boundaries to have subjectivity), merely that extant 'rules' were not taken as rules to follow, but guidelines to merge, expand upon and reform. This expansion and merger has occurred by uniting the thematic analysis observed in grounded theory with discourse analysis techniques. As highlighted in chapter 4, both of these approaches are critical of one another.

Rigour and validity is also performed by clearly laying out how the rules of analysis were merged with and expanded upon from previous techniques for data analysis, demonstrating how analysis proceeded throughout this chapter with an extensive collection of appendices. In addition an account of how the researcher influenced the data production process is traced through this chapter. The final decision of whether rigour and validity has been produced (and with it a viable researcher) is therefore left up to the reader(s) of this thesis, rather than making any direct claim to external measures.

5.8 Introduction to sample

To give the subsequent findings chapters context, some of the broad social and demographic findings are presented here. Discussion around how this limits the findings is reserved for chapter 9.
5.8.1 Final sample details

Table 5.1 shows a summary of the final sample according to: diagnosis, age and gender. Individual participant’s details can be found in appendix Z. The average age of participants was 69 years with a range from 48 – 98. Comparing this data to the 2003/4 data (the last collected on a national basis) on district nursing (Department Of Health 2004) this sample differs from the average district nursing population:

Table 5.1 Summary of demographic data

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Carer Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>Malignant = 18</td>
<td>Mean = 70</td>
</tr>
<tr>
<td>Non-malignant = 6</td>
<td>Range = 48 - 98</td>
</tr>
<tr>
<td>Co-morbidity = 1</td>
<td></td>
</tr>
<tr>
<td>Undisclosed = 1</td>
<td></td>
</tr>
</tbody>
</table>

Table 5.2 Comparison of national age ranges of district nursing case loads versus age ranges for this study

<table>
<thead>
<tr>
<th>Ages</th>
<th>Percentage Nationally</th>
<th>Percentage for this Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-24</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>25-34</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>35-44</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>45-54</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>55-64</td>
<td>11</td>
<td>23</td>
</tr>
<tr>
<td>65-74</td>
<td>18</td>
<td>50</td>
</tr>
<tr>
<td>75-84</td>
<td>29</td>
<td>19</td>
</tr>
<tr>
<td>85 and over</td>
<td>21</td>
<td>4</td>
</tr>
</tbody>
</table>
However, this national data covers all district nursing contacts, not just patients with palliative and supportive care needs. There is no nationally collated data for numbers of palliative care patients on district nursing caseloads. Therefore, the representativeness of this sample is difficult to establish due to the outdated nature of these statistics and their lack of specificity to this research. However, this is not problematic for this study as within post-structuralist understandings age is merely a construct that has no natural meaning or bearing on reality. Just as gender is considered to be performed, so can age, rendering chronological age irrelevant pushing analysis to examine discursive aspects rather than chronological aspects of age. Therefore, whilst demographic data was collected such as age, gender, occupation and diagnosis (all listed in appendix J), unless such factors appeared to overtly affect the data, for example in terms of discrimination, it is not considered within this study for analytical purposes.

Assessing whether a sample was ‘representative’ of the population by placing arbitrary external constructs onto participants assumes that these external constructs such as ethnicity, gender, age, race, class occupation are unproblematic. Infact they are problematic and have no clear definition. Therefore, when considering representativeness, one needs to question what ‘representativeness’ is aiming for in qualitative research. If representativeness is something that fixes the participants identities with external discourses that were not of their making and may not form their identity, then assessing for ‘representativeness’ can begin to be viewed as immoral both as an act directed towards the participants, and as a method of analysis. Instead, demographic factors as they were performed by participants were assessed for whether they did or did not have a clear effect on the identity of patients and carers. Only those that did for that particular participant made it into the analysis.

5.8.2 Diagnosis
One such factor that did affect the care of patients was diagnosis. As can be seen from table 5.1 only six patients had a non-cancer palliative diagnosis with
one co-morbidity. Figure 5.1 also demonstrates that recruiting through a variety of community nurses was of only limited success in increasing the numbers of patients with a non-cancer diagnosis. In addition I would often be asked by district nurses whether the study was for “non-cancer patients”. Even posing such a question suggests biasing a palliative and supportive care study towards only cancer patients would have been thinkable. Therefore, after being asked this question several times I endeavoured to impress on all potential healthcare professionals that the study was open to all their patients regardless of diagnosis however this was met with limited success as can be seen in the sample.
Chapter 6

The paradox of ‘busyness’

6.1 Introduction

The aim of this chapter is to explore how ‘busyness’ forms a pseudo-quality care; care which appears to be of a high quality but is in fact a conceptualisation resulting from the restrictions placed on patients and carers subjectivities through the discourse of busyness. It will explore this by examining which discourses reform the subjectivity of the district nurse and how these discourses can result in the patients and carers subjectivity being exceeded or restricted. A critique of the morality of the care is given suggesting that even the banal actions of district nursing affect patients and carers and have moral dimensions which affect care. These banal actions are explored through the time keeping practices of district nurses and tracing these actions through to the broader discourse of busyness examining how it (re)forms patients, carers and district nurses in immoral ways.

6.2 Timekeeping – known time and date, or only known date

Timekeeping is split into two categories with variation within them. Participants who knew the date and the time the district nurse was visiting, and those who only knew the date the district nurse was visiting. No patients or carers reported not knowing a date or a time, i.e. district nurses arriving unannounced.

A few patients had very precise appointments:
“C17: Like when he goes they say we’ll come at such a time, and every time they said they’ll come, they come.”

However, most patients were not given an exact time, but instead a time slot. These time slots varied from anything from one hour:

“C16: So, you know, they’d say it’ll be between two and three.”

To much vaguer time slots where specific hours were not stated:

“P13: No, they don’t give you a time. But they did say verbally we’ll come in the morning.”

A few participants only knew the date the district nurse was visiting:

“P7: they come every other Monday, and you never know what time they’re coming”

The variety of time keeping practices went on to affect quality care in a variety of ways, often depending on their social and medical circumstances.

6.3 Effects of timekeeping on quality of care:

Some patients were frustrated with the inaccuracy or unpredictability of the district nurses visits, stating that knowing the time of a visit made their daily routine easier to adjust and cope with:

“P14: If you’re not feeling 100 percent that morning and you could do with an extra hour in bed, so if you knew that they were coming at 11 you’d only need to get up [then].”

However, for other patients fixing a specific time was irrelevant because they were housebound or nearly always in the house:
“P19: [timekeeping] doesn’t matter really because I’m in the house all the time except for Tuesdays or Thursdays when I’m out at [local hospice] but other than that I’m in the house.”

It is possible to draw the conclusion from the interviews that patients and carers prefer to know the times when district nurses are going to visit unless they are house bound in which case it isn’t of much consequence because they were in anyway. However, by taking a post-structuralist view this analysis is drawn to look not only at what themes emerged, but how timekeeping is read through a variety of other discourses and how these go onto (re)form the patients and carers subjectivity. It will then be explored to what extent these are moral (re)formations.

6.3.1 Organisational requirements

In the following case P12 knew when the district nurses were coming to take bloods and give injections:

“Interviewer: The timekeeping of the district nurses. Have you known when they’re coming and to what…?

P12: No, I haven’t. When [district nurse] was doing bloods I knew that she’d always be here before about ten because the blood samples need to be at the GP surgery … and when I had the clexane they used to come at dinnertime.”

Yet not when doing other tasks:

“P12: when the district nurses were coming to do the dressings and things you’d no idea what time they were coming”

There was an implicit theme amongst participants that organisational and biomedical directives were justification for giving an accurate time for visits. This in itself cannot be considered ‘wrong’ as to do otherwise may risk physical
harm to the patient. However, within a post-structural analysis it appears that biomedical and organisational requirements become ways of forming district nursing. Specifically, biomedical discourses were privileged above other discourses such as psychosocial care. If therefore patients and carers construct a nursing subject who is primarily motivated by biomedical discourses they, as subjects of the district nurses, become dialectically formed within this discursive (but unwritten in policy terms) hierarchy of care. Such effects on the patients’ and carers’ identity can be seen in the lack of evidence that patients felt district nurses were obliged to do psychosocial care, whilst it was felt as lacking, patients did not challenge the lack of care that they received:

“Interviewer: So you were talking to the district nurses about feeling depressed. Did they do much about that when you mentioned it to them?

P19: No, as I said, they just talked about me going to [local hospice] and asked me if I had any family or what not coming, friends and what not, and that's it basically.

Interviewer: So do you feel they needed to do something, or do you feel you'd already got support?

P19: No, I think they could've possibly done something, because they were the first people I'd talked to about…then it just got worse.”

Where it did occur it relied on biomedical treatments as a way in rather than being a task in and of itself:

“Interviewer: the district nurses coming in, do they spend much time chatting with you?
P18: No…not over and above…whilst they’re treating, yes…when they’re not treating me, they go, don’t they, because they’ve got, well, they’ve got heavy calls to make, whatever.”

Carers often form a similar implicit devaluing of psychosocial support:

“C3: I was signed off sick… so I was at home most of the time and I saw most of the district nurses coming and going, got to know some of them quite well, occasionally, they would talk to me about how are you? You know, how are you doing? But, obviously, they’re most concerned about P3… they never specifically came to talk to me and it’s been the same right to this day and that’s what I expected, to be honest… Although, there’s been one district nurse who is based…well she’s based at [PCT B] now, she was at [local town], who has…she’s probably been the most regular of all of them, she came very regularly in 2008 and she has been a couple of times this year after P3 was discharged and she would occasionally… after she’d seen P3, she’d come downstairs and say, how are you getting on? Are you alright? So, I appreciated her for that.”

In addition some patients also felt chatting and social visits took time away from other patients:

“P1: Now, for them to come and sit and spend five or ten minutes talking to me they could well have seen another two patients in that space of time.”

Importantly no patients or carers ever felt that physical care such as dressings or injections took time away from other patients. In addition, very few patients saw it as a failing of district nursing to not chat and offer psychosocial support. Such silences in the data about chatting being valuable but not always carried
out suggests a hierarchy of care where physical care is always legitimate but psychosocial care not always so.

One way in which this hierarchy may be (re)formed is by nurses delivering accurate times for certain care and not for other types of care making some aspects of care more important to not only the district nurse, but to the patients and carers who are the *dialectic subjects* to the district nursing discourse. This shifts the *subjectivity* of the patient to one where they themselves privilege biomedical and organisational procedures over other needs. This results in patients not presenting their psychosocial needs to the district nurse because to do so would be an unviable action:

“Interviewer: So when they were doing your insulin were they coming in and just doing the insulin?

P19: Yes, just doing the insulin, yes.

Interviewer: And did they spend much time talking…

P19: No.

Interviewer: It was just…

P19: Yes, that's it, give you your insulin and off.

Interviewer: So in and out.

P19: Yes, that's right, yes.

Interviewer: Was that okay for you?

P19: Well, no, I'd preferred them to stay a bit and talk a bit, spend a bit more time.
Interviewer: Well, how long and what sort of things do you think you'd have talked about or preferred to have talked about?

P19: I don't know, just how... how I was feeling and whatever. Is there anything else that they could be doing. Maybe, I don't know, it depends. I know it was only insulin, but spend about ten minutes or something. It was get it in and then off we go! [chuckles] Be as quick as we can.

Interviewer: So I'm wondering, did you feel you had opportunity to talk to them about those things?

P19: No, I didn't, because they were so quick. Like I say, it would've been nice just to have a bit of a chat, is there anything else I needed. But they seemed a bit too busy.”

Busyness and the way in which certain tasks are legitimated by the organisation of district nursing over other tasks serves to restrict patients ability to ask for or access additional care which they may require, but that district nurses do not overtly offer.

6.3.2 Prioritisation

The discourse circulating that some work was implicitly more of a priority than other work served to (re)form district nurses subjectivity into one where district nurses were not expected to give an accurate time for their visits:

“P7: They never know what phone call they're going to get in the morning that's a priority so they have to put their priority before people like me... It's not a priority to be flushing your line out but if someone's got - like this pacemaker, where it's burst open or something and it's pouring blood, they're a priority.”
This quote shows that the *subjectivity* of the district nurse places limits on what quality can be. In this case, the same patient suggested that district nurses deal with pouring blood, which can clearly be read as district nurses dealing with emergencies. However, the same participant recounted the same incident previously in the interview but in significantly different language:

“P7: They came every other week, as I say, and I just had this put in. I told them, ‘it's [pacemaker] bleeding’… so straight away [the district nurse] said, "let's have a look at that first, then". They hadn’t come to see my pacemaker on that day. Straight away they looked at that and saw what it was and said, "no, it'll be okay, it’s just the congealed blood from after the operation" and that’s what all the redness was and all the blood that was seeping out.”

The discursive reality that the pacemaker was “pouring blood” and was an “emergency” is (re)formed in the above statement. Instead the patient mentioned the pacemaker asking the nurse to examine it because it was bleeding. Importantly, the idea of “bleeding” does not evoke the same kind of ideas of emergency as “pouring blood” does. Why then can the same story be told in two very different ways? It appears that the story of the pacemaker has been rewritten in a confusing and contradictory way to try and understand nurses timekeeping. By positing that nurses deal with emergencies P7 rewrites district nursing. This results in him being unable to make a clear statement about their timekeeping:

“Interviewer: One thing I've been asking people is about the timekeeping of the district nurses.

P7: Now, that is one problem. It probably not a problem - that’s the wrong word, I shouldn't say that. I’ve said the wrong word there, it's not a problem. I said the wrong word there…”

Declaring it a problem then immediately rebuking himself suggests
that his unedited opinion is that it is problematic. However, the subject he has constructed (a district nurse dealing with emergencies) in turn constructs him altering the way in which he conceives his own care:

“P7: the only thing is they say they're coming on Monday, because they come every other Monday, and you never know what time they're coming so you're sat here waiting for them.”

The discourses that circulate about district nurses doing emergency type care disciplines his descriptions of the district nurses’ actions. Instead of them being problematic, they become merely a function of the fact that they are dealing with emergency situations and therefore he becomes a patient who sits and waits for them without complaining. To do otherwise could be considered selfish when one’s own care is of a lower priority than others. This (re)formed reality of district nursing precludes many forms of critiquing district nursing practice.

6.3.3 Laziness

Re-writings of nurses which result in uncritical praise can sometimes work in the opposite way. P20 presents a particularly interesting case:

“P20: I have these patches on right, now they are supposed to be on nine o’clock in the evening till nine o’clock the next morning, so they come when they feel like it in the evening, if they want to get off early they are here at eight o’clock, other than that it could be half past ten. Mornings are the same, could be eleven o’clock when they come. Now the carers come in and want to shower me, so the patch is on, so how do you have a shower with the patch on?”
The idea that nurses may be delayed with other urgent cases is not absent in P20's account, but the way in which this urgency comes to form her idea of what a district nurse is and how she evaluates her care in relation to it is quite different:

“P20: Maybe they have an urgent case somewhere else, but there is not just one nurse, I can't go so you go to [P20] or, in this day and age there is mobiles, no excuse and I don't go along with excuses I'm afraid. They could do it in my day when, I'm sure they can do it in this day and age. I mean they have a lot more staff to see to things for them... one came in one night and said, well she'd had an emergency, sorry she was late about quarter past, half past ten. The next night she'd forgot what she said the night before, oh she'd been busy... That was the night before so she forgot that she was late the night before... they think that we are all, if we turned a certain age group then we don't know what we are doing and we don't know what we are saying and we need telling what to do, well I'm afraid I don't accept that.”

P20 produces a very different district nursing subject, mainly because she herself had worked as a district nurse for a short time before spending the rest of her career as a surgical nurse. Whilst she recognises that ‘urgent cases’ exist, she rejects the idea that this can have a regular impact on her care. The knowledge that she has of district nurses, namely that there are multiple nurses who all have mobile phones, leads her to conclude that urgent cases cannot be a good reason for their repeated poor timekeeping. Instead she draws on discourses that other participants did not have access to, namely her own personal experience and interpretation of nursing:

“P20: I covered a wide area of different things in my career. I mean in that day and age it was slave labour when I first started believe me, with the cleaning night bottles and that...
and wards and goodness knows what you were cleaning in those days, as well as doing your job and no compensations for this… [nowadays] in nursing, caring, it’s let’s get the money in, that’s all it is today and so and today they don’t give a hoot as to whether if, to give respect to somebody that’s terminally ill in the general wards, it’s terrible.”

These two quotes demonstrate that P20 considers quality nursing to consist of a desire to care which has been subsumed into a desire to make money. This results in P20 reading similar situations to P7 as signifying poor quality care.

Juxtaposing P7’s case with P20’s using a post-structuralist framework drives this analysis to examine what is making viable subjects and thinkable thoughts in relation to quality of care. Whilst many discourses circulate around district nurses constantly (re)forming their subjectivity, the one which seems most influential and ubiquitous relating to many examples of district nursing care is busyness. Busyness appears to operate on the thoughts that patients and carers are able to produce and the subsequent actions of the district nurse.

6.4 Busyness as a paradoxical discourse

One of the overwhelming discourses that circulated in the interviews with patients and carers was that district nurses were busy. The following questions are addressed in this section:

- What are the limits to thinking about district nursing care?
- What avenues of critique are open and closed to patients and carers?
- What ways can they be allowed to think otherwise about themselves?
- What do patients and carers become in dialectic relation to their district nurse?
- What does the district nurse become in dialectic relation to the patient and carer?

Because of the complex interlinking ways in which they interact they will not be dealt with under individual headings, to do so would result in them being
presented as discrete topics which stand on their own which is not the case. What is being put forward is in fact the complete opposite, each facet is linked inextricably to the other continually creating a reality of district nursing and continually placing limits on what quality is and can be. Therefore, these questions will be answered in a narrative that reflects the interwoven nature of the complexity they represent.

In the interviews conducted it was clear that busyness was one of the most dominant discourses that went into constituting the district nurse subject but this was achieved in two different ways. Firstly, in a direct way nurses claimed to be being busy to the patients and carers:

“P18: There’s no way they can commit themselves to any length of time.

Interviewer: Is that something they have explained to you that… I think… or something you’ve picked up on or…?

P18: Oh yeah, I picked it up on… they mentioned it, I mean, I’ve said, jokingly, oh, you’re running a bit behind today! Oh, we’ve been very busy, we’ve had an emergency or we’ve had this happen.”

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“We phoned the district nurses and they said, ‘we’re terribly busy today’”

However, this direct claim from the district nurses of being busy was relatively rare, instead patients and carers more often layered the discourse of busyness onto the district nurse to explain other actions:

“P5: Yeah. I know they do a good job and they’re busy, you know, because I always say, you know, do you want a drink or
something, you know, I think it’s only once when [district nurse] had a drink off me.”

The district nurse declining a drink could be read in a multitude of ways, for instance she may just not be thirsty after having just had one at the previous house. However, instead it is read as a ‘busy’ district nurse even though there is often little to no evidence for it which the patient can cite. Busyness therefore begins to fix and control what patients and carers think and feel about district nurses. Whilst sometimes it is the district nurses declaring busyness which shapes what people think of district nursing care, often, there has been no declaration of busyness, and instead busyness serves as a discourse to delimit the space in which patients and carers can think about district nurses controlling what can think about a wide variety of district nursing actions.

In relation to district nurses providing psychosocial support some patients’ thinking was restricted and cut off because of ‘busyness’ (re)forming district nurses:

“Interviewer: Do you think it would be useful for them to just come and visit you? From your point of view, not from theirs, from…

P16: It would be a confidence builder, yeah. But that’s all. You know, it would take too much time on, NHS time, so, I wouldn’t expect that to happen… but I didn’t expect them to stay long, ‘cos I expected them to be busy. So I never questioned, you know, ‘why have they rushed off?’”

IV medication administration was cited as something that two patients (P14 and P26) would find beneficial from district nurses. However, in the case of P14/C14 it was rejected as possible because of busyness:
“Interviewer: So do you see that in the future the district nurses, do you think their role might change from just doing the line? Do you think they might start doing other things?

C14: I think they could do… I think it’s [administering IV medications] something they could offer, whether they’d be able to offer it I think is a different thing cause you just see that they’re so busy now.”

Finally, busyness not only made unviable non-physical district nursing care or future care such as IV medication. It also made unviable current physical care which in the previous chapter was demonstrated to be core to the district nurses subjectivity:

P19: On some occasions my wife's been here when they've said it, 'oh, well, we've not been told to do it, we're busy, we've got a lot of jobs on, would it be possible to do it [leg dressings] tomorrow? We'll tell someone to do it tomorrow.'

Busyness therefore appears to have the potential to make almost any nursing action unviable and served as one of the major ways in which patients subjectivity became restricted and controlled by a discourse which dialectically (re)formed themselves and district nurses progressively restricting new acts occurring. In this way care becomes immoral and cannot be said to be quality care.

6.5 Busyness: becoming docile-patient, becoming immoral-nurse

Patients and carers appear to become more docile because of the idea that the district nurses are busy, they either don’t ask for different and extra care, or don’t challenge less than desirable ‘problematic’ care. ‘Docile’ in this case
specifically refers to Foucault’s ‘docile’ subjects’ (Foucault 1977; Foucault and Gordon 1980) who are so entirely formed by power/knowledge that they self police in accordance with the laws that form them. It appears that patients and carers not only (re)form the nurses subjectivity as a ‘busy’ professional who may not have time to undertake various tasks, but also (re)form their own subjectivity by reflexively being (re)formed by this ‘busy’ district nurse discourse cutting off their ability to conceptualise their care otherwise, becoming docile subjects. Busyness in itself as a discourse reforming the district nurse can be said to be morally neutral. However, when we begin to look at the effects of busyness and how it restricts district nursing care its immorality becomes clear.

For example, when participants were asked what they thought district nurses could do for them in the future, despite many being open and honest about their approaching death and what it would entail; very few had any clear idea of what their district nursing care would become. P25/C25 demonstrated the clearest idea of what district nursing care may become when she is in the last days and week of life:

“Interviewer: So do you feel that the district nurses could do anything more for you if you became more unwell at home?

P25: Well, I suppose they would do, yes, definitely.

Interviewer: And what sort of things do you think they might do?

P25: Well, I don't know, Maurice, it just depends what it is that I have. I don't know, I suppose they'd look after me.

C25: I mean nobody's ever told you that, have you?

P25: No.

C25: So you don't know what to expect for when you get…
This quote demonstrates that C25 and P25 realises to some extent what death will entail, however P25 only gives a very vague “I suppose they’d look after me”. The grammar in this statement is in itself telling, in that she is not certain, it is merely a supposition that the district nurses will ‘look after’ her. P25 and all other participants were unable to envisage what else district nurses could do for end of life care.

Many other patients had no notion of what their district nursing care could become if they were not dying but if their illness and needs changed. Instead they appeared to enter into a realm of fantasy where district nurses could become anything, do anything and be faultless:

“P7: I honestly can't fault them as a team or anything, they're superb. There's nothing too much trouble for them… They were saying that the help is always there, they'll always be there for me and they'll provide it.”

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“Interviewer: Okay. I'm wondering, is there anything else that you feel you want to mention about the district nurses?

P10: I can't think of anything that they didn't do, or anything that they could have done any better, really.”

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“Interviewer: Yes. Are there any things you think they're unable to help with then?

C17: There's nothing really...

P17: I'm sure if we needed help they would help us… If we need them they come, if we want anything…”
Whilst this may appear at first to be moral, the idea that district nursing can become anything and do anything without fault renders district nursing unintelligible. Butler (1997a) is clear that there must be limits to discursive positions in order to bring a subjective position into being, in this case district nursing. District nursing must have some limits and cannot ‘do anything’. How then is this limitless district nurse produced and maintained if it is in itself unviable to have such a discursive position?

If a highly docile subjective position is dialectically reformed and maintained by patients and carers as a reaction to the ‘busy’ district nursing subjective position; then the discursive position of the nurse is faced with a docile patient-carer subject which does nothing to try and change or reimagine district nursing care. The district nurse is in turn dialectically formed as being without limit because the docile patient-carer never attempts to find or place limits on the district nursing subjectivity. This limitless district nurse against a highly limited patient precludes any ability to develop care in new directions yet paradoxically produces unbounded praise for district nurses where district nursing emerges from patients who have reformed the nurse as ‘doing anything’ and quality care becomes pseudo-quality care. Whilst such a paradox is not always as stark and clear in all the cases presented in this study, ‘busyness’ being performatively enacted by nurses effects the subjectivity of the patient and carer and their ability to challenge their care under healthcare services. This therefore constitutes a form of immoral care. If patients are unable to re-imagine their current subjectivity by the fact of their subjected docility then the very basis of the patient-carer-nurse triad and the care that occurs within it is immoral. Once the care can be seen as immoral, the ways in which this immoral care functions within current healthcare systems can be assessed opening up possibilities of producing a less docile more powerful patient and or carer subject.
6.6 Moral district nursing care, becoming-other:

Whilst busyness has been examined to demonstrate immorality in district nursing work, merely deconstructing care in this way declaring it immoral is only half the work. What about moral care?

Moral care should produce a subject which can become-other. In order to do this the discourses that form the district nurse must not result in a docile patient-carer subject. This becoming can be achieved though reforming the district nursing subject to remove the barriers which produce docile patient and carer subjects and (re)forming the district nurse with discourses that allow change and development. Three cases will now be presented to demonstrate what moral nursing may look like: becoming friends, becoming counsellor and becoming younger. These cases will show how discourses that reform the nurse have the effect of opening up new possibilities for the patients and carers subjectivity rather than closing them down in the way that busyness does and are therefore considered moral rather than immoral.

6.6.1 Becoming friend or relative:

The notion that district nurses can and do become friends or relatives was at first a surprise, particularly as it came from the first participant, however several other participants also described the nurse as a friend or even a relative throughout the research interviews yet the case of P1 remained one of the clearest cases to demonstrate the effects of the discourse of friendship:

“P1: When I did start to need them the sister came out to see me along with a couple of other district nurses and they introduced themselves and what-have-you and they observed my wife doing a drain and they were quite happy to leave her to it. They just said would I mind if they came back a few more times to observe that, you know, it was being…and we became…I wouldn’t say we’re good friends because we’ve not known each other that long, but I feel as though they are a
friend that I can talk to if and when I ever need to…it’s been very…I won’t say laid back and relaxed because that wouldn’t be professional, but it has been relaxed and it’s put me at ease when they’ve been giving me any treatment or advice…possibly one day I will need their professional expertise a lot more than I do now and if we have a good working relationship now when it comes to the time where I will need them I feel I know I can trust them to do whatever’s necessary when it’s necessary and they know they can do whatever they need to do without upsetting me or the wife”

Here P1 began with the nurses coming to do a physical care task, this was the case for all but one of the participants, P4. Where district nurses began with a physical care task they were not considered friends, but slowly through a variety of actions they became friends. This allowed the patient to declare in a moral way as discussed in chapter 2, ‘I am not that [a patient] I am this [your friend]’. Whilst the discourse of friendship can restrict in much the same way any other discourse can, in this case friendship allowed existing subjectivities to be exceeded and so can be considered a moral way of reforming subjectivities and related care. In the above case P1 envisages nurses helping him in the future and this is facilitated by the friendship that has become his district nursing service. Therefore, friendship can be seen to be a moral discourse and a moral way of being because it opens up new possibilities and new actions for the patient to explore.

6.6.2 Protecting the home
As well as having the potential to open up new possibilities, the discourse of friendship (re)forming the district nursing subjectivity can have a protective effect on maintaining the environment of the home:

“Interviewer: Yeah. But does them coming into your home change how your home feels or…?”
P2: No, they just feel like friends.

Interviewer: Okay.

P2: You know, they’re so easy to talk to. It’s like having a friend come in…. You know you can always ask advice and everything, you know.”

This contradicts the arguments put forward by Liaschenko (1994, 1996, 2000) in a series of philosophical arguments, not empirical research, that nurses intrinsically affect the home environment bringing biomedical discourses in creating a hospital from the home. This suggests that nurses have an intrinsic ‘nature’ that brings with it a biomedical discourse. Examining this through a Butlerian framework it can be seen that the premise of Liaschenko’s article does not always hold true. In the case of P2 a moral way of being was demonstrated by the district nurse in that she became friends. This in itself can be considered moral by allowing such an act to take place, however, its effects can also be seen to be moral in that it prevents the home becoming purely a site of biomedical concern. This is not to say that biomedical discourses are in themselves immoral. They are not, and provide the very basis for the nurse to be viable within the home environment; the morality lies in allowing the nurse to become-friend, which allows the patient to become-friend in turn protecting the home environment and opening up possibilities for conversations which can happen with both nurses and friends.

6.6.3 Reshaping but remaining nurse:

Whilst friendship can be seen to (re)form the district nursing subjectivity and have positive effects on psychosocial care and the feeling of the home, the district nurses are not fully reformed by friendship, instead they exceed their subjectivity but do not escape it:

“Interviewer: So what would you say the district nurse has become to you then? Do they remain fully district nurses, or does the relationship change at all?
P24: No, they remain district nurses, but kind of friends in a sense, when you’re seeing them for so long, you know, not friends like friends that you go out with but you know what I mean it’s, you feel like you can kind of tell them things and, you know, if you’re not feeling so good, you know, not things that you keep to yourself, you know, you feel you can say to them, oh look is this something normal I don’t feel too good and if they don’t know they’ll, I feel that they would maybe speak to the doctor and say look Denise feels such and such. You know, that kind of thing because you’ve built up that kind of personal relationship, because you’re seeing the same ones each time”

Exceeding subjectivity in this way allows a space for friendships to open up and propagate allowing actions to flow from this novel subjective site which may not have occurred from a site purely formed within the initially performed physical discourses of district nursing. However it also allows district nurses to remain nurses and carry out actions associated with nursing. Therefore, the district nurse becoming-friend can be considered moral in that it allows patients to engage in care which is required, but may be unviable within extant discourses of district nursing.

6.6.4 Becoming counsellor

Whilst becoming friend at times facilitated (re)formation away from physical district nursing tasks, some patients also noted that district nurses specifically became-counsellor at certain times. However, in order for this to be viable it always remained tied to physical care:

“I interviewer: Right. Have they ever visited just to come in and not do a dressing but just sort of come in and sit?”
P12: No.

Interviewer: So there’s always been that physical reason to be coming in, albeit they have sometimes counselled.

P12: Yeah.

Interviewer: I’m just wondering…how do you feel about there always being that physical reason?

P12: I’d be more…I think I’d be shocked if they turned up on the door and just said we’ve come for a chat. I personally I wouldn’t expect it. Coming back to, like you say, how you perceive a district nurse, it is to do a physical thing… I wouldn’t expect a district nurse to come unless there was a physical reason for them to come to do something physical that you can’t do…I do think the district nurses, as good as they are, they don’t have the time. The two that I picked up on that did the counselling on me, I mean, like I say, the one of them I think she just realised I was probably at quite a low ebb, so I think that was important for her to recognise that.”

P12 therefore recognises the limits of district nurses, that they aren’t there to only perform psychological care. Instead, the viability of district nursing lies in physical care. Psychological care is allowed because it is a (re)formation of district nursing which commenced within the extant discourses of physical care. As previously argued limits are not in themselves immoral, they allow the forming of a viable subject. Instead morality lies in allowing the patient to become-other, in this case, becoming a person who needs psychological help. However, what is key with the case of P12 was that there were viable performances of district nursing prior to the performance of psychosocial care. The case of P4 demonstrates that without these viable performances of extant discourses, psychological care may be unviable:
“Interviewer: Did you have any expectations of what the district nurses were for or what they might do for you before they came?

P4: No, none whatsoever, none whatsoever.

Interviewer: Yeah. And had you heard of district nurses?

P4: I’d heard of them but I just thought they went around dressing wounds and stuff like that, you know.

Interviewer: Yeah. And, so, just to talk about that initial meeting again, so, they came to visit you, can you just tell me a bit about what happened there?

P4: Yeah. Well there was two of them came, introduced themselves by name, one sat on the chair, the other sat on the bed with notes and they basically said they worked in the area.

Interviewer: Mmhmm.

P4: And then whatever else they said, I don’t know, because I latched onto a note that was hanging off one of the boards stating…I’m trying to read it and its saying, in the last stages of terminal illness, P4, and after that, I just switched off to them.”

Importantly P4 did not appear shocked at the terminal diagnosis:

Interviewer: Yeah. So had you ever considered your illness like that before?

P4: Well, COPD had told me about it.

Interviewer: Right, okay. Had they used those words?
P4: Oh yes.

Interviewer: Okay.

P4: Mm, I’ve come to terms with… death

The effect of this was quite dramatic in that she then rejected the entire notion of receiving any care whatsoever from the district nurses:

“Interviewer: So if I can just clear this up in my own head, even if there were things that they were…

P4: Capable of.

Interviewer: Was within their role and were capable to do…

P4: I wouldn’t want them to do it.”

Reading this through a Butlerian lens we can see that the district nurse entered the home and was already a discursively formed being, the ‘traditional’ district nurse, one which did dressings. When P4 was faced with a nurse who had come to only ‘talk’ the district nurse was quickly outside of the discursive space of legitimate district nursing. The fact that the talk involved terminal care and that it was read on a note could be understood to be the reason for such a violent reaction to the district nurse. However, this would not be reading the whole case in its context. This participant was very open about her illness and her impending death, mentioning it to myself within minutes of being in the room therefore, to consider this the only reason for her rejection of the district nurse is a somewhat unsatisfying analysis. Instead it could be read that the district nurse was rejected because her actions were not viable within the discursive space of the ‘traditional’ district nurse. Psychological support and terminal care discussions were not something that P4 expected and nor is it
something that strongly circulates about district nurses. Therefore, to undertake such actions without any actions such as physical care risks making the district nurse unviable in the home unless some form of discursive (re)formation of the district nursing subject proceeds such ‘early support visits’. Additionally, P4 was the only case where the initial contact of the district nurse was not couched in a discourse of physical care and was also the only case where the district nurse had been rejected giving further weight to argument that the discursively formed viable space of the district nurse restricts the viability of actions that can initially done. Instead, as in the case of P12 whilst moral care should allow exceeding of the patient and carer, the district nurse must first become viable using physical care discourses.

There are important implications of practice when comparing these two cases. Whilst the district nursing literature suggests that district nurses value early support visits, there is no evidence from this research study that early support visits happen for patients with palliative and support care needs. Instead district nurses have always been involved initially for physical care reasons and at times acted in a moral way to reform their and their patients subjectivities to ones which include psychosocial support. However, it can be seen that if this initial viability is not established, then district nurses may be rejected. Therefore, if early support visits are to succeed there needs to be a change in the extant discursive formation of the district nurse. Exactly how this can be achieved will be explored further in the next chapter.

6.6.5 Becoming younger – the thesis of morality:

One participant, P17, described a whole sale change in his identity when chatting with the district nurses:

“In this case, it's important for them to get to know you as a person?”
P17: Well, I would think so, yes. If it was something more serious and more technical they would have to get to know me more, but this is only minor… I laugh with them… It's nothing serious, nothing sore… They have a laugh with me and treat me…that's all, yes…

Interviewer: And is that an important part of their work for you?

P17: I think so, yes. I think so. And to cheer me up or even other patients and to cheer them up …As they come I don't feel old, I feel the same age as them.

Interviewer: How so? Why do you end up feeling the same age as them?

P17: Well, I talk the same, having a drink and going out and…I never have a drink now, [chuckles] I used to go out, I enjoyed it. And their husband's fishing, and I used to like it with the fishing, and I thought oh, just chatter like.”

In this case, it is not possible to trace a direct effect on P17's care and how its quality is enhanced in terms such as allowing psychological support, building confidence in end-of-life care, or any other healthcare service. This therefore represents possibly the most moral act; becoming for the sake of becoming. Often, even when patients and nurses became friends there appears to be justification in the nursing literature that building a relationship is beneficial for care and facilitates psychosocial support and assessment (Seale 1992; Griffiths 1997; Austin et al. 2000; Seamark et al. 2004; Sandgren et al. 2007). Therefore, even this becoming-friends or becoming-counsellor still resides within the district nursing discourse. Becoming younger however, does not, it therefore represents the most original and most distinct exceeding; and as such represents the thesis of moral care. Importantly however, the district nurse in this case remains viably a district nurse by engaging in caring for a chest drain. Therefore, viable morality is maintained despite the actions having little to no bearing on the biomedical care that is being given.
6.6 Summary

This chapter has demonstrated how day-to-day activities and practices such as time keeping and organising physical care become read through the discourse of busyness; even though alternative readings were often possible. Busyness has been demonstrated to restrict patients and carers *subjectivities*, preventing them from *becoming-other* producing and maintaining docile patient and carer *subjects*. In addition, all viable district nursing care was revealed as always being predicated and based around physical care. No evidence was found for successful early support visits which did not include physical care. The next chapter considers how *power/knowledge* contributes to maintaining this visage of busyness.
Chapter 7

Power/knowledge

7.1 Introduction

*Power/knowledge* forms one of the theoretical cornerstones of this thesis, and prompted questioning around patients’ knowledge of their district nursing services. However, the thematic analysis of patients’ and carers’ experiences of district nursing care confirmed that knowledge that patients and carers have plays a key role in how the reality of the district nurse is (re)formed and the subsequent care that was given. This was an overarching theme that widely influenced patients, carer and district nurses and what follows is an exploration of knowledge and how it comes to (re)form the subjective positions of patients, carers and district nurses. Particular attention is given to how the circulation of knowledge can be implicated in producing moral quality care and how these subjective positions shift and thus how patients and carers are often unable to critique poor quality immoral care.

7.2 Extant circulation of knowledge on district nurses:

Whilst documents such as the NICE supportive care guidelines (National Institute for Clinical Excellence 2004) specify what district nurses should be and do for this patient and carer group, unsurprisingly patients and carers never made reference to such documents. Instead, patients and carers made occasional reference to television programmes, newspapers, fictional literature and previous experiences with friends and family as forming their understanding of district nurses prior to their first encounters with district nurses. Patients and carers expressed two understandings that they had of
district nurses prior to them coming into the home. That district nurses give hands on personal care:

“P2 bath people in bed and things like that, you know”

And biomedical care such as wounds, dressings and medications:

“P4: I just thought they went around dressing wounds and stuff like that”

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“P3: “[District nurses] were there perhaps to help sort out tablets with patients. Not actually get them for them but help sort out their confusion with tablets.”

Occasionally this came from previous experience of district nurses where they had cared for relatives but there was often uncertainty attached to how accurate their understanding was:

“C3: I remember them coming to help my parents as well at odd times when they were both ill, they both had cancer and died some time ago but that’s about all I can remember prior to that.

Interviewer: Can you remember much about the district nurses back then when you met them with your parents?

C3: Well, I think I understood that they were just a mobile version of hospital nurses, I don’t know if you…really, that’s my crude way of thinking.”

However, most patients and carers suggested that they had gained understanding from mass media such as television programmes and newspaper articles:
“P17: Is all these nurses are not the same then? I’ve heard there's nurses going in people’s houses and they boss them and all sorts of things, and not nice to them, and these what come here are not like that at all.

Interviewer: Where have you heard that from then?

P17: Only from different people, I read in the papers, probably seen it on tele and different little…all sorts of things, yes. Like hospitals, and they batter patients and not clean them for weeks and that, I read that in the papers and saw it on television. So that's where it's come from, nobody I know of like really.

Interviewer: Have you ever read good news stories about district nurses and things?

P17: No, there’s not any good ones put in the paper, is there? Only in the paper is all the bad ones, like I’ve never wrote to the paper and said how good they are, so that's what happens I think, doesn't it?”

Media appears to circulate knowledge of district nurses and many of the extant discourses that patients and carers had of district nurses were congruent with those portrayed in mass media where district nurses are legitimately concerned with areas of care such as wound care (The District Nurse Episode 1 18:46 - 19:47) and washing, dressing and medicine administration (Jones 2008). Knowledge from historical encounters with district nurses in a palliative and supportive care role often reflected care which occurred pre-1990 under the NHS community care act (Department of Health 1990) and knowledge from mass media was either skewed towards negative sensationalist stories or more dated than their own experiences. Whilst knowledge from these sources was acknowledged by patients and carers as being questionable at best, it
was often the only knowledge that patients and carers had of district nursing services which was independent to the district nursing service. Therefore, even if patients and carers had had previous contact with district nurses or had a body of knowledge built up with mass media representations of district nurses it often served little in the way of giving them any sense of power or knowledge over their contemporary district nursing experience.

7.3 Knowledge restricting action of district nurses

Knowledge of extant discourses on district nurses therefore cannot be considered to give patients and carers any power to direct their own care:

“P4: I think their role…I’d hate to say their role be expanded wouldn’t it, but I think, like myself, not knowing that they do certain things it will increase their role. Perhaps they wouldn’t like that. But it would increase people’s ability to access the things they had.”

Whilst the previous chapter has argued discourses and knowledge produces subjects, lack of knowledge also appears to produce patients and carers who reside in a reality where other services and acts of district nursing cease to exist by district nurses creating a silence on other care:

“P12: [the district nurse] explained the service and that they’d been asked to come to deal with the dressings…then obviously they did the blood tests for me for the chemo, and when I went on the clexane, I mean they used to come every day and do that until I got to the stage where I could do it myself. But they’ve always sort of turned round and said if you’re having problems just
give us a ring and we’ll come. You know, they’ve been brilliant. I can’t really…

Interviewer: So when you say they explained the service what sort of things did they say to you?

P12: Well they’d say obviously that if you need, you know, we’ve been asked to come X amount of times a week to do these dressings and obviously, you know”.

The ‘obviously’ stated by P12 covers for a lack of knowledge which P12 has about the district nursing service beyond which they were already performing (in this case dressings). Whilst (as discussed in the previous chapter) the initial bringing into being with physical care discourses is important as it produces a viable subject, it becomes immoral when it remains unchanged through a lack of knowledge, precluding other possibilities by reducing and excluding knowledge on district nursing services. The knowledge gained by patients and carers through the performances of district nursing comes to form the district nursing subject and in turn dialectically forms the patients and carers subjectivity; from the empirical data it appears that this knowledge is nearly entirely one within physical care discourses. Knowledge on any other services was never reported to have been provided verbally or in writing to patients and carers by district nurses.

7.4 Reforming knowledge of district nursing services

It is not knowledge in itself that is important, but the ways and extent to which barriers are reduced and knowledge is given access to that creates quality moral care. Two examples, equipment provision and psychosocial support will be explored to demonstrate how a lack of knowledge prevents access to these two different elements and how access to knowledge is controlled by district nursing services.
7.4.1 Equipment provision

Many of the patients interviewed had restricted mobility which equipment such as walking frames or wheelchairs could help with. However, many were unaware that these could often be provided by district nursing services, with the questions in the interviews prompting them to discuss this with their district nurse:

“Interviewer: Have they ever sort of organised anything for your home like equipment?

P3: No. And C3 said this last night, about equipment for the home. He said they haven’t … I was thinking then some things sometimes could have been quite useful, but they didn’t suggest it… I’ve kind of forgotten that I can borrow things off the district nurses or loan things from them… I’m going to write this down.”

Other patients acknowledged that district nurses had a role in providing such equipment but had no knowledge of how to contact district nurses:

“P13: I had a terrible time getting off and on the loo [post-operatively at home]. Not getting on, it was okay, getting off… I have to sit higher up so I can push myself up. And down there I've got to really pummel to get up. But the first couple of weeks was bad for me.”

During these first couple of weeks, P13 had no knowledge that district nurses could have provided equipment. It was only when the district nurse came to remove surgical clips that district nurses then went onto provide equipment. Therefore, equipment provision can be understood as an aspect of district nursing care which does not circulate in the same way as wound dressing (which was circulated by hospital staff to P13). However, there were some patients and carers who were provided with equipment and saw nothing unusual or different about it:

“Interviewer: Have the district nurses ever provided you with
any equipment or anything?

P11: Yes they have.

Interviewer: Okay. What sort of stuff have they provided for you?

P11: They provided me with a backrest for the bed…. they brought me some slide sheets.”

Equipment provision appears therefore to be a socially viable discourse for district nurses to occupy which makes it accessible to patients. However, knowledge of it as a service is still required for it to be instigated by patients or carers as it doesn’t appear to be something that exists discursively prior to the district nurse entering into the home and hence does not exist for patients and carers unless knowledge of it is distributed in some way.

7.4.2 Psychosocial support

Psychological support was not a discourse that any participant felt was overtly within the remit of district nurses:

“Interviewer: So when you said they explained the service, they explained the physical care that they could give and the office hours, you mentioned that counselling thing. Was something that was overtly mentioned or something that was sort of covertly done?

P12: No. I think one of them one day started asking me things and what-have-you and she was sat there and I sort of twigged and I thought she’s doing a bit of counselling on me.”

Whilst this was offered, its offering was controlled by the district nurse, not
asked for and accessed by the patient. In this case however, it was still felt to be timely:

“Interviewer: So do you feel that…obviously there’s this district nurse that came in and did counsel and one that did refer to [Hospice C]. Prior to that do you feel it was missed or sort of dodged, or did it come at the right time?

P12: I don’t think it was missed because I don’t think I probably realised that I was quite low.”

However, this timeliness of district nurses was not always the case for other patients:

“Interviewer: So you were talking… [with] the district nurses about feeling depressed. Did they do much about that when you mentioned it to them?

P19: No, as I said, they just…talked about me going to St Catherine’s and asked me if I had any family or what not coming, friends and what not, and that’s it basically.

Interviewer: So do you feel they needed to do something, or do you feel you’d already got support?

P19: No, I think they could’ve possibly done something, because they were the first people I’d talked to about…then it just got worse.”

This lack of district nurses doing something is explained by the patient considering it outside of the district nurses role because P19 lacks knowledge in relation to district nurses caring for depression.
“Interviewer: Do you feel they avoided talking about your emotions and your depression?

P19: No, I just think that they…well, I presume they don’t know much about it and what not, I don’t know. See, I don’t know what they’re qualified…and what they’re doing and whatever, I don’t know.”

This adds another dimension to a lack of psychosocial support being given to patients and carers. Whilst it has been suggested that some district nurses avoid psychosocial issues, literally “moving swiftly on” (Griffiths et al. 2010: 394), patients’ and carers’ lack of knowledge that district nurses may offer psychological care, coupled with no clear declaration by district nurses that psychosocial care is within their role (unlike the statements surrounding physical care) comes to reinforce the reality of district nursing as physical practical carers. Therefore, whilst district nurses give knowledge out about their service being concerned with physical issues, psychosocial care needs remain outside of the knowledge that circulates about district nurses and that patients and carers subjectivities are (re)formed within these discourses.

Psychosocial care also always arose from the interactions that patients had with district nurses for physical care tasks:

“Interviewer: So they’ve been coming to do the pump?

P7: To flush my line out, take the pump off and see to any scars and everything I’ve got. They would have to come when the lines first go in because they have to keep your line clear, as I say, take the stitch out of there. I’ve also had one in my neck here where they put the line in so they have to see to that stitching and everything. There’s quite a lot of work involved and, of course, when I had this pacemaker fitted they had to come and sort all that out - redress it and all that.
Interviewer: So far you’ve described quite technical tasks, I suppose might be the word. Do the district nurses do other things with you when they come?

P7: They discuss if there’s any bothers about my treatment or anything. They always allay my fears. One thing I am terrified is - I don’t think I’m frightened of dying but I’m frightened of the nature of my death. This is what I said to the nurses, I said, ‘you know, they’re in agony even with morphine, they’re still in agony’. They said, ‘we’d make sure you get fully dosed up’…they’ve assured me that I’d be basically pain free. They’re very good in giving advice on something like that.”

Psychosocial care for patients was therefore not absent, but was either concurrent or adjacent to physical care tasks; whilst the physical care was acknowledged by district nurses, the psychosocial care was not. However, carers’ support needs were almost absent even when there were clear needs and carers were present in the house:

“I interviewer: It sounds like, sort of, at one point you’d have been in the home, at the same time, for quite a lot of visits is that…?

C3: Yeah, I think it might have been one and a half, two months, or something, in the middle of 2008…

C3: I’ve always understood that they’re there to help the patient first and foremost, if the carer is having problems it’s with the carer to find their own solutions. So, really, that’s what I’ve done…[I didn’t] know anything about district nurses until, you know, days before she was released and the hospital staff started talking about them…

Interviewer: so how did you come to, sort of, having that expectation that really they’re coming for the patient, primarily?
C3: Well, it was just what I noticed when they came into the house. I think, from memory, once P3 came home from that first operation, I went into work in a flat spin, I was very stressed and confused by all this and I was signed off sick, GP put me on anti depressants, so I was at home most of the time and I saw most of the district nurses coming and going, got to know some of them quite well, occasionally, they would talk to me about how are you? You know, how are you doing? They never specifically came to talk to me and it’s been the same right to this day and that’s what I expected, to be honest. Although, there’s been one district nurse… she’d come downstairs and say, how are you getting on? Are you alright? So, I appreciated her for that…”

Allowing the carer to become a site of psychosocial support and offering him the knowledge that district nurses can provide psychosocial support for carers can be viewed as quality care. However, the covert nature of it appears to still prevent carers approaching district nurses directly for their own needs:

“C3: I’ve always understood that they’re there to help the patient first and foremost, if the carer is having problems it’s with the carer to find their own solutions.”

Such an understanding of the subjectivity of the carer and their viability as subjects who can legitimately access psychosocial care can be read as being because their knowledge of district nursing services creates a patient subject with primarily physical needs who is the foremost concern of the district nurse. This dialectically forms the carer as an unviable subject of district nursing care because they do not have any physical care needs from the district nurse; if they did then they would cease to be fully a carer and instead become a patient of the district nurse. This knowledge is built up by the carer not though policy documents and reading, but by experience and the performances of the district nurses. Literature on the ways district nurses perceive carers is limited, but what does exists suggests that they value building ‘positive relationships’
(Austin et al. 2000). Therefore, whilst district nurses may claim in the literature to be concerned with carers, in their practice they appear to perform discourses which whilst engaging with the carers exclude them as a viable subject of care. Restricting knowledge on district nursing care can therefore be seen to produce an immoral subjectivity forming subjects (patient and carer) who have little or no autonomous access to care.

In contrast to equipment provision, knowledge and acknowledgement of psychosocial care is much more restricted. For example, patients gained knowledge of the nurses psychosocial care skills not by nurses declaring their willingness and ability in this area, but instead by nurses covertly doing psychosocial care. It is neither declared prior to its doing, nor even when it is being done. Instead, unlike equipment provision, it is something which is on the edges of the district nursing role, something which the nurse needs to tentatively explore the boundaries of, performing it but never fully declaring it, rather than confidently inhabiting it. This covertness resulted in psychosocial care always needing some form of physical care to be considered viable and as the case of P4 suggests, psychosocial care is not fully viable for a district nurse to do on its own. Such covertness keeps knowledge of psychosocial support offered by district nurses away from patients and carers creating a hierarchy of who is able initiate certain types of care. For example patients had no concerns about initiating care from district nurses for physical needs:

“C15: The district nurses are at the end of the line, and that’s like a… buffer really to know that they’re there, you know, if I needed…because I’ve rung up sometimes just to ask them something…

Interviewer: What sort of things have you rung up to ask them, out of interest?

C15: It was only the other day, when his catheter wasn’t filling up, it was just about that much… so I’d rung about midday to say that he wasn’t experiencing any pain or anything like that but what should I do. And she said give him a couple of cups of water, you know, extra fluid really and see what happens,
and then ring back. And they came that…it was actually in the evening they came because when I rang, I said there was no…he still wasn't experiencing any discomfort. But then I did ring later on to say that he was, and then they came out to see him.

But it’s just kind of reassuring, you know, if you’ve got somebody there at the end of the telephone line that you can, you know, find out if that’s normal or not normal really. I can’t think of another instance actually, but I have done.”

It can be seen that knowledge of physical care from district nurses, whilst not always clearly available, is not unviable for patients and carers to explore. However, no patients suggested that they would seek psychological support from their district nurse. This places psychosocial support out of the reaches of patients and even further out of the reaches of carers who were rarely approached or offered any form of psychosocial support and never directly approached district nurses seeking it. Instead their knowledge on district nursing care was restricted within an understanding that nurses were predominately there for the patient with physical needs, not the carer.

7.5 Imagining future care: viable yet immorally restricted subjectivities

Patients and carers not only needed to access care that they currently needed, but because of their diagnoses, most acknowledged that their physical health would change over the coming weeks, months and years to one where they would require further assistance. This section examines what knowledge patients and carers had of the services available from district nurses in the future that they could access. It is explored with words and phrases that they may directly link to their death and the process of dying, and/or words and phrases that are not. Questions such as “is there anything else that you think they [district nurses] might do in the future then?” did not use the words ‘death’
or ‘dying’ in relation to future district nursing care and helped explore the boundaries of patients’ and carers’ knowledge on district nursing within a framework of palliative and supportive care but without restricting it to death and dying. For some patients this phrase was used instead of directly asking about future care in relation to death and dying because they themselves had not used this phrase. For others it was used as a way to explore the future and subsequently ask more direct questions around death and dying if the topic was or had been raised by participants.

7.5.1 Care not directly linked to death and dying:

In relation to ‘future care’ most patients were unable to think beyond what district nurses were currently doing for them:

“Interviewer: So are there any things that you think the district nurses might be able to help you with…either now or in the future?

P19: No, I don’t think so, can’t think of anything. [pause] What they do if I’m not so well”

Such expressions of uncertainty were almost ubiquitous and appeared to bear no relationship to the patient’s or carer’s awareness or willingness to discuss their illness in terms of death and dying. Instead it appeared to rely on whether district nurses and other community healthcare professionals had proactively engaged in and offered knowledge of future services that the patient may require:

“Interviewer: So the district nurses started coming to do…

P14: The portacath…”

-167-
Interviewer: Who’s idea was that, do you mind me asking? Why did that come about?

P14: Well I did ask… it was a progression of talking about the IV services and the community matron didn’t feel they wanted to do it. They were the same, there was only one of them could do it, and I didn’t need any of the other services so they then decided they’d hand it over to the district nurses, and they’re happy with it… they want to get involve more with portacaths and IVs [IV antibiotics] and things like that.”

In this case, it is clear that the patient had engaged in several conversations with community matrons, district nurses and hospital staff about line care and IV antibiotics being done at home rather than hospital. This enabled the patient to expand on these conversations and helped her realise that her future care could be conducted in alternative ways. Being made part of this conversation and being given the ability to gain knowledge on what district nursing service can become appears to be a marker of quality palliative and supportive district nursing care for patients with palliative and supportive care needs. This however, remains one of the few examples where patients were given knowledge to imagine district nurses becoming involved in their care in alternative ways. To put this another way, patients’ horizons of knowledge about district nursing were fully encapsulated by the district nursing that they had already received and were unable to think beyond it.

Carers presented similar issues but with some subtle differences towards how knowledge directed their actions:

“C6: Like we found out with P6 things they can do for him… it’s just the district nurses you phone up, but I can do it for him anyway. We don’t like putting on staff if we can do it, we will do it, because they have enough work to do as it is… mean we do what we can and if I think I can’t do it for him, then I would phone the district nurses because they’re brilliant… [if I couldn’t] have got him into bed and get him undressed, it takes
more than one to do… Yes when we know we need them we won’t call them out willy nilly, I mean if he was bad with his breathing I wouldn’t call them out and say his breathing is bad, will you come out, I know what to do, they have explained to me what to do and I know I can do it, and until that time comes when I can’t do it, that is when I would have to call them out, but no we cope.”

In this way the knowledge/power of district nurses maintains a carer who reduces and curbs the involvement of district nursing services whilst retrospectively covering up this act. This could be read as either positive or negative, but deferring such value laden conclusions for the moment enables the analysis to uncover how carers’ knowledge both of district nursing services and the patient has been crafted to produce a subjective position which only minimally intersects with the district nurses. Whilst appearing to give power to the carers, it also simultaneously draws away the district nursing service only making their presence viable under specific pre-ordained circumstances.

7.5.2 End of Life Care

Only two patients and carers out of the 26 had a clear idea of what DNs could do for them at the end of life. This was not in the main because patients or carers were in denial about their diagnosis and prognosis; in fact most to varying degrees were open, honest and broadly realistic about their diagnosis and prognosis. Only one patient (P8) and one carer (C21) didn’t acknowledge ‘end of life’ aspects to future care.

Patients’ knowledge of care relating to death and dying:

Patients were able to articulate quite easily rationales for their preferences for care. In some cases however it didn’t appear that this was based on a full understanding of district nursing care and instead was related more to anxieties about how carers would cope with caring for them at home:
“P26: Well, I wanted to be at home when I was first making my mind up what I wanted, you know, get things into gear when I was first diagnosed and, I said, I wanted to be done at home but, thinking of C26 and how he panics and how upset he gets and if he’s there and, with the kids, it would be harder for him than if I was in a hospice and because I’m coming to hospice for over a year, I’ve asked them, if the time comes… we’ve put our name down, that, if possible, we’d like to be here [hospice] when the time comes.

Interviewer: Yeah. What would your second preference be, then?

P26: Home… Just don’t want to go back into hospital at all.

Interviewer: Okay. So, there’s been quite a lot of discussion about future.

P26: Yeah. And, as I can’t do more, the more they’ll [district nurses] put into place for me.

Interviewer: Okay. And do you have an idea what that more is?

P26: Well, I don’t, because I don’t know what I’m going to need, really, you know, it’s alright saying, oh, well, I’ll probably need this and I need that and I probably won’t need that, I’ll need something else.”

P26 represents patients who with more knowledge on the district nursing service may make different decisions about their care. Whilst P26 suggests that her decision for not having a preference for home care is because her husband would ‘panic’ there remains a lack of knowledge on what district nursing care could provide in the future. In this case this lack of knowledge
may be restricting P26’s ability to understand and direct her district nursing care redirecting her desires for end of life care to a place which she has more knowledge of, the hospice. One patient P7 had a clear idea of what care could be offered at home:

“Interviewer: To talk about the district nurses themselves - do you have any idea of what they might help you with in the future if you become more unwell? Do you have any idea how they might help.

P7: Yes, they’ve already told me that, as my illness progresses, they will be looking after me. That’s what they said, "we’ll make sure you get sufficient morphine to stop any fears you’ve got and if we have to come every day, so what?". They were saying that the help is always there, they’ll always be there for me and they’ll provide it.”

All other patients were unable to conceive in any detail how end of life care might work at home with P24 providing a cogent example of how this wasn’t an ideal situation:

“P24: Yeah, and is somebody going to tell me that that’s what happens… I think is somebody going to tell me once Christie’s say there’s nothing else we can do… it’s just, at the end you do kind of worry, is it going to be a case of a district nurse who will come in every day and give you pain relief, or is it just that you would just ring them up if you feel you need, I mean, you can’t really answer those questions because I know I’m not at the end yet, but it’s just things that do go through your mind.”

Whilst patients didn’t make a direct link between this lack of knowledge and the quality of their care, it can be argued that the lack of knowledge that patients have in regards to district nursing services relating to death and dying causes unnecessary anxiety which is preventable. The restriction of knowledge and its subsequent restriction of what patients and carers can be results in anxiety where needs are unmet and is a marker of poor quality care.
Carer knowledge of care relating to death and dying:

Carers equally faced a similar lack in knowledge on care relating to death and dying, and as with all other aspects of care their knowledge related to the care of the patient, not to the care of themselves:

“C16: to me, if you are bed bound you would want to see the district nurse, wouldn’t you?... Do you know what I mean? I suppose they come and wash you and all that, don’t they, when you’re bed bound? …Give you medication and things like that. Or do they just have carers for that now?... The district nurses don’t do that sort of thing now do they?”

The way in which this whole exchange was in question form, rather than clear statements reflects the uncertainty and lack of knowledge that most carers had regarding district nursing care. However, in addition to this lack of knowledge some carers faced the additional barrier of rarely having time on their own with the district nurse:

“C10: I’m aware of what's likely to happen towards the end as she is and she is hoping to get into the Hospice for the terminal bit.

Interviewer: [Pause] So you feel the district nurses can help with the pain?

C10: Oh they can definitely help with the pain.

Interviewer: Is there anything else you think they might help with?

C10: Well I don't see anything else really... because anything else other than the pain, it would be impossible to get somebody else to get involved - she needs to go to the toilet, she needs help with anything then it’s going to be me so.
Interviewer: Right okay and have you spoken to the district nurses about that?

C10: No because I can't do that in front of Pauline and she's always here.”

Restriction about what services are or aren’t available restricts the choices that carers feel are open to them. In-patient care appears to be inevitable because district nurses will only help with pain relief. The situation of whether that particular district nursing does or doesn't provide a particular service is irrelevant to the argument that lack of knowledge is driving decisions rather than service provision and patient or carer empowerment.

Whilst it could be argued such conversations may be difficult to conduct jointly with patients and carers without having time to allow individuals to express their private concerns and worries, in only one case was it almost impossible due to living arrangements for the nurse to have time alone with the carer. This is reflected in the joint interviews of P6 and C6 which was conducted in the front living room, to do otherwise would have required asking the carer and the patient to sit for up to an hour in a less then comfortable environment on a high chair in the kitchen when neither of them were well enough. The living environment of P12 would have presented similar difficulties but her carer declined to be interviewed and wasn’t present in the house during the interview. Therefore, in the majority of interviews there was adequate space for confidential conversations to occur with both patients and carers and all that was needed to achieve this was to politely request time alone during interviews.

7.6 Distributing knowledge

If knowledge is a key factor in determining quality care then who is responsible for its distribution and drawing the limits on what is knowable about district nurses? How might this be challenged to distribute knowledge and produce moral care for patients and carers with palliative and supportive care needs?
It seems that there are multiple sources of information on district nurses some of which were noted by patients such as district nurses, other healthcare professionals and other patients. Other written sources such as the internet via official government sites or third party sites and information leaflets, whilst containing information on district nurses were never mentioned. The relative merits of each of these sources will be critically examined below.

7.6.1 District nurses

As already discussed patients receiving information from district nurses tended only to be given information on care that they were already receiving, which was always born within physical practical biomedical discourses. Whilst such grounding in these discourses is necessary for district nurses to be viable within the home of the patient, by district nurses not fully distributing knowledge on the other services that district nurses can perform, patients' needs go unmet. In order for quality moral care to occur therefore nurses need to engage in conversations that more fully explore and allow for novel connections to be made about district nursing services and patients' and carers' needs. This would need to occur with some regularity as the changing needs of patients may alter what care they would wish to access from district nurses. However, this runs the risk of being idealist. Therefore alternative sources of knowledge need to be promoted which offer opportunities for patients and carers to gain knowledge about their care independently from the district nurses and emancipate them away from the rigid framework that their care originated within.

7.6.2 Other healthcare staff

In relation to palliative and supportive care only one case gained information about district nurses from other healthcare staff:
“Interviewer: I was just trying to find out how you found out what the district nurses did, how you came to your current understanding that they can come in?

C6: It was [the community matron] and the heart failure nurse that talked to us about these wasn’t it?

P6: Yes.

C6: What they can do with him not wanting to go into hospital, unless of course he had a heart attack, then he would have to go, because there is nothing the district nurses could do for that, it’s if he gets to the stage where he has took all his medication and he still can’t breathe then they come out and they can give him different medication.”

This represents the only case where patients and carers developed knowledge on the district nursing care whilst being under their care from other healthcare professionals. There were however several cases where patients were due to be admitted for chemotherapy or major surgery, and would, in all likelihood, require support at home and in retrospect would have valued knowledge of the district nursing service prior to their respective medical interventions:

“Interviewer: Did the district nurses come and visit at all when you were having the chemotherapy?

P17: No.

Interviewer: No?

P17: No. Oh, that chemotherapy, when that came on, pff, don’t want to go through that again! I couldn’t eat, I couldn’t sleep, I couldn’t walk and I couldn’t talk for a full week. I had that
thrush in my mouth, and those steroids I was taking, oh, they were…I’d never want that again.

Interviewer: Because you said the district nurses didn’t visit when you were having the chemo; do you think it would’ve been useful to have had district nurses come?

P17: It might have been, because I was suffering that week. I was suffering, I had to go to my GP for my…and that thrush in the mouth, and I didn’t know what pills I was taking or anything. I could’ve done with a lot more help then, every day then, but I had to go to the doctor once, and get the pills from the chemist. But it didn’t work I don’t think. I wanted mouth washes, I wanted…If the nurses were coming then they could’ve seen to all that, couldn’t they, I think…

P17: What he’s saying, C17, just think what he’s saying; he’s saying when I first came out of hospital after chemo, would the district nurses have been helpful to me?

C17: Well, probably they would.

P17: I’m certain they would.

C17: There’s one down the road, isn’t she, she’s a district nurse.

Interviewer: Was it that you didn’t know that they could’ve been…

C17: We didn’t know, that’s the trouble, we didn’t know. All I was concerned about was him.

P17: Knowing what you know now, would they have been helpful?
Disseminating knowledge about district nursing services therefore cannot be entirely the responsibility of the community care team when they may have no knowledge or reason to have knowledge of the patients and carers existence. Instead, in such cases information on district nursing services would need to be given prior to patients discharge from or even admission to hospital:

“P12 (interview 2): the district [hospital based] nurse liaison nurse, if they know that someone’s being discharged, you know, maybe they, it could be their point of call. Yeah. I mean I do think some sort of information, you know, with contact numbers, emergency numbers, you know.”

Such basic information provided by hospitals may prevent some of the discontinuities in care between patients and nurses, but it would not contribute to the problem described by many patients of not knowing the extent of the district nursing service. As all hospitals and many GPs deal with patients who receive care from a wide range of district nursing services, relying on other healthcare staff to provide anything beyond basic information on specific district nursing services could risk ‘disappointing’ patients and carers. However, this assumes that emancipation is related directly to providing knowledge. Instead, the power and subsequent restriction of subjectivity that comes from district nurses possessing all knowledge on district nursing within the patient-carer-nurse relationship could be eroded to an extent by other healthcare professionals encouraging patients and carers to think in new ways about their district nursing care, encouraging critical thought in what help they may need at home and how district nurses could provide this for them. Such activity occasionally occurred during the interviews for this research, instead of declaring what district nursing services did or didn’t provide (in the majority of cases I was broadly unaware) I instead reflected the question back. Whilst this was generally aimed at exploring the limits of their knowledge rather than
encouraging them to think otherwise about how they could engage as patients with their district nursing service, some patients were able to think otherwise and suggested that they might contact district nursing services.

7.6.3 Other written information

No patients or carers received any written information about district nurses that went beyond basic names of district nurses and contact details:

“I: Has anyone ever sat down and talked to you about the [district nursing] service?

C21: No, no.

I: And you’ve not had anything written about the service?

C21: No.”

P14 was the first patient to raise the topic of an information leaflet as a solution to a lack of knowledge:

“Interviewer: Right, okay. And would you like to have a better idea of the service?

P14: Yes. I think then you would know how much you could access it, you know, and how much there is there to access should I say, not that you actually do want to access it, but if you do need anything whether it would be available through the district nurses or not. Because you don’t actually get any leaflets about your district nurses as such, you know, it’s just they come out to do the job and that’s it really.

Interviewer: Have they ever spent much time telling you what the service is or is it…?”
P14: No. Just about, you know, we’ve come to do your portacath and this is what we’re doing sorting it.

Interviewer: Right, okay. So how do you think you could best learn more about the district nursing service then?

P14: On what they have to offer you mean?

Interviewer: Yeah.

P14: Perhaps a leaflet. You know, just to say that these services are available from the district nurse.”

However, the exact form that such an information booklet or leaflet should take is less certain. This is because it was something that was explored later on in the data collection period and it is not felt that this topic reached data saturation, subsequently it was only explored with three patients (P14, P24, and P12 [second interview]).

A parallel is draw with hospice services where information leaflets are given:

“Interviewer: Yeah. Have you had that sort of thing with other services then?

P14: The hospice service, we get a leaflet off that for the day therapy, we always get the…but the community matron, we didn’t get any leaflets or any information about it”

Patients who were asked (P24 and P12) felt that they would be comfortable receiving a leaflet stating the words ‘palliative and supportive care’:

“Interviewer: I want to ask the last few people I’m interviewing, would it have upset you getting leaflet saying district nursing palliative care?

P24: No, no… No it wouldn’t because even ten years ago they told me without chemo that I wouldn’t last six months, I had the chemo, I was very lucky that it gave me five years, so
if I’d have had a leaflet then, no, it wouldn’t have worried me, I’d have just known that that was, you know, the fall back, who would look after me if the chemo didn’t work… once you get cancer you think, you don’t necessarily think you’re going to get through it, sometimes it goes through your mind that you’re not going to get through it, so, no, I think it would be a good thing to know what there is there, what there is to help you.”

Within this study such a result isn’t that surprising considering that the information leaflet had the words “palliative and supportive district nursing care” on the front page. Further research is clearly needed to assess what wording would be effective and non-distressing, but the preliminary research in this study suggests that such pre-emptive information would be acceptable to some patients. However, because there were no reports of the wording of the study information sheet upsetting potential participants it can tentatively be suggested that disseminating written information on district nursing palliative and supportive care is unlikely to upset many of the patients and carers on district nursing case loads and may instead reduce the distress of uncertainty around how their diagnosis and prognosis interfaces with the district nursing services.

7.6.4 Other patients and carers

There were two instances of peer learning about district nursing services (P12 and P26), notably at a hospice day care centre. This suggests that such exchanges are generally quite rare. Only P12 was able to describe any specific knowledge exchanged that went beyond vague abstract descriptions:

“P12 (interview 2): when I went back to the hospice after I’d seen you the last time, and I spoke to one of two other people who are on the day therapy with me. And some of them had horrors, district nurses that were horrors, you know. They wouldn't come out and do pre chemo bloods or anything like that. Now I never had a problem with any of that with mine.
They just used to, you know, give us a ring and we'll come. You know, they were lovely. You know, but there was one lady and she was an older lady and she said, oh she said I have to go to the health practice. I said well do you not just ring up and say you’re want pre chemo blood. She said oh my God they won’t come out for that. So I think mine were a nice bunch.”

This conversation reflects the lack of exchange that generally occurs between patients about district nurses. P12 had only engaged in conversation about district nurses because of the study that she had taken part in. Once conversation began to occur between patients it was easier for them to critique practice which had up to that point been status quo and uncritically accepted. Further research and service development may benefit from building on this type of patient to patient exchange about district nursing palliative care services by utilising focus groups.

7.7 Summary: structurally immoral care

Within the discussion above it has been demonstrated that the knowledge that circulates and the discourses enacted by the district nurses come to form a specific form of nurse-patient-carer triadic subjectivity which privileges physical patient care. Lack of knowledge has been shown to produce a clear power imbalance where district nurses produce and (re)form the care that is given whilst restricting knowledge beyond the immediate physical care discourse. This discourse itself doesn’t preclude moral care being given, in fact it allows the process of caring to viably begin, but the continued restriction of knowledge by district nurses does.

The subjection of carers is doubly restricted in that carers not only need to shift from the reality of being a carer to the patient but also the reality of being a carer who assists the district nurse precluding them being a focus of care
themselves. In addition their speaking, and hence their way out of this restricted *subjectivity* is further constrained by co-consultations with patients which may not allow conversations to take place. Whilst several sources and potential sources of knowledge exist for patients and carers, the ways in which this knowledge is circulated remain problematic.
Chapter 8

Morality of maintaining the home

8.1 Introduction

As discussed in chapter 5 some findings arose through the thematic analysis of empirical data with post-structuralist theory. This chapter differs in that the collection of the data was strongly influenced by Liaschenko’s (1994, 1996, 2000) theoretical ideas about the home as a place that is changed by nursing care prompting questions directly about whether and how nurses effected the home. It is acknowledged that for the majority of the participants it was more than just the district nurse who entered the home (agencies such as GPs, MacMillan nurses and social service carers also form a part of ‘home care’). However, district nurses are the focus of this thesis, and therefore, any discussion of other agencies is not undertaken in this chapter. Instead this chapter aims to explicate a previously unexamined link between how care affects the home, and how home affects care, tracing the morality of their dialectic development.

8.2 The home in death

The idea that the home is the ‘natural’ place of death has been put forward by several authors (Bowling 1983; Higginson and Sen-Gupta 2000; Gott et al. 2004; Barclay and Arthur 2008) but always in a way that fails to question what is natural about the home as a place of death and why it may be considered natural. In this chapter it will be argued, that ‘the home’ is neither ‘natural’ as a place of death nor a static concept. Instead the home will be examined in a similar same way to how Butler examines gender as the ‘natural’ basis for understanding sexuality. Driving analysis to understand what discourses about
care in the home are performed by and (re)form the patient, carer, and nurse yet come to appear ‘natural’ and unable to be articulated. Through a similar process Liaschenko’s theorisation of the home as pre-existent and hence given ontological privilege in analysis is critiqued.

Post-structuralist theorisation leads to an understanding that the home is constantly already being reformed and that nursing care as such is not necessarily a disruption but may instead be considered a reformation. In this way, the home, the care in the home and the subjects involved are not considered static. Instead they are constantly performing and repeating ‘the home’ suggesting theoretically that the home is not natural but merely maintained with different sets of discourses. A post-structuralist analysis will therefore aim to: explicate what these discourses are, how they affect the home, how they affect the quality of care in the home, and what can be said about the morality of any reformation of the home and the discourses that maintain it.

8.3 The district nurse and the viability of the home

As discussed viable district nursing always began with a specific task such as wound dressing or injections serving as a way for district nurses to become viable in the home. In addition, there was never any possibility of alternative providers for home care. Therefore, a certain unilateral inevitability made district nurses viable providers of care within the home, yet a perception persisted that patients chose district nurses. However, the home also began to be the inevitable place of care:

“P18: They said with the advancing years, they need to know would I go in a hospice, would I go in a nursing home, would I go, etc, etc, I said, no, I’d prefer to be at home… with elderly people now, they’re tending to go for treatment at home, wherever possible, from the cost point of view, amongst everything else, and, also, from the patient’s point of view.”
This remains a complex and ambiguous quote. It can be seen that patients are beginning to perform the discourses of increasing home care, accepting the home as the best place of care. This discourse appears to be bleeding into the discourses (re)forming patients *subjectivities*. That “cost” is accepted as a valid reason (alongside patient choice) suggests neoliberal discourses of efficiency in healthcare are also combining to (re)form home care as a viable place of care. Even though other discourses are available they are not performed by patients. In addition to this the concept of choice becomes eroded:

“P23: I had no choice because I couldn’t do the injections myself, and I didn’t have anybody to do it for me, so I asked if I could get up in the morning and take it to my surgery, but the doctor says no because they would be nobody there to give it to me at weekends. So that’s how come I had the district nurse in.”

The subjective positions made available become characterised by inevitability and lack of choice. Therefore patients have little influence over who cares for them because there are no other providers who can carry the medically necessary tasks of medicine administration in evenings and weekends; home care for certain types of care becomes efficient and inevitable.

8.3.1 The right type of illness

However, this inevitability always began with a specific set of conditions; district nurses are therefore made viable in the home by patients having a task needing completing which extant discourses dictated district nursing can address. Therefore, for patients to initially have access to district nursing care they must have the right type of illness. This instantly places a restriction on their identity by inevitably linking care with district nurses to a narrow set of tasks, precluding the possibility of becoming other by only having recourse to discourses around being a certain type of patient. Choice as an idea in healthcare is present and forms *subjectivities*, but the inevitability of the district
nurse reforms it into a pseudo-choice which is limited through its initial activation and then further limited by district nurses needing to maintain a viable identity in the home.

Viability of district nurses in the home is therefore outside of the influence of patients and carers and extant discourses (such as injections) (re)form the home as a place of care. Therefore, whilst the home has become viable, it is only through placing restrictions on the patients' subjectivity which directs care to the home away from other possibilities. This in itself cannot be considered immoral as viability in itself requires restriction. Instead morality lies in how district nurses facilitate or preclude the expansion of the discursive viability of the home from its initial becoming as a site of biomedical care.

8.4 What makes home care unviable

To examine the morality of the (re)formation of the home, it must also be examined what and how limits produce the home; this will help examine what the current limits to morality are. These were more often linked to the patients' health (rather than the service that district nurses could provide) such as acute and severe illness precluding district nursing care. The only factor which was always represented as the district nurses limiting home care was IV therapies.

8.4.1 IV therapy

Without access to IV therapies at home it was felt that the home was no longer a viable place for care to occur.

*P26: Sometimes all I need is…to have to have [IV] fluid, I have to go in [hospital] for it.*

Patients commented that IV therapies (both antibiotics and fluids) would benefit them and enable care to continue at home.
“Interviewer: What's the main thing that you would need to stay at home then?

P14: IV antibiotics I should imagine. Because I've got my oxygen, but it's just… the antibiotic.”

However, IV therapies are represented as facilitated or restricted by district nurses with patients and carers having little influence over IV therapy:

“P14: They [district nurses] weren't happy at first I don't think a few years ago, but now everything’s changing isn't it, you know, they want to get involve more with portacaths and IVs and things like that.”

Whilst authors like Liaschenko (1994, 1996, 2000) argue that the technology for IV care to be given alters the home environment, for a small subset of patients, it was felt that IV therapies given by district nurses would maintain the viability of their home; expanding its discursive limits and producing moral care. This maintenance was shaped by district nurses, not patients and carers. Therefore expanding the role and power of the district nurse into IV therapies at home could be understood (even with the subsequent increasing in technology) to be producing quality care by allowing the (re)formation of the home. However, the lack of power/knowledge that patients and carers had to reform their home in this way suggests an immorality in the way that care is structured by precluding them from producing such discussions with their nurses.

8.4.2 Illness: producing and precluding district nursing care

Illness, whilst initially making district nursing viable in the home, is also represented as something that can prevent district nursing care in the home when it is either ‘unexpected’ or ‘severe’. Unlike IV therapies which are linked to the capacity and capabilities of the district nursing services, illness as a
reason for producing or precluding district nursing service is linked to patients; who in palliative and supportive care have little to no influence over the course of their illness.

*Unexpected illness*

Several patients described episodes of unexpected illness that meant district nursing care was no longer a viable option.

“P25: Yes. But I mean every time I've been admitted to hospital they couldn't have treated me here because I've been admitted with that many heart attacks that they have to get you away, hadn't they? I was rushed in a few months ago… every year I've been in hospital since my husband died, haven't I, it's been one thing or another.”

Whilst district nurses often provided the majority of care for patients at home, it was not always district nurses or patients who made decisions about whether care could be managed at home. Instead it was other healthcare professionals (often GPs and community matrons) enforcing a particular regime of *power/knowledge* about where and when care should be directed to:

“P19: It was last week that my hand started swelling up, and they'd [district nurses] noticed so they phoned my doctor, doctor came out and said that I needed to go into hospital.”

In such cases, the hospital admission was not read by patients as being due to district nursing. Instead it was read as a medical necessity, best practice, which exceeded district nursing and the home. Such medical discourses become performed by the district nurses by allowing greater privilege over other discourses, such as a desire to remain at home that was expressed by some patients and carers:
“P19: I'd rather spend my time at home with the family than in hospital with a load of strangers.”

Even though in many cases it wasn’t the district nurses diagnosing and directing care, it could be argued that district nurses need to allow patients and carers the opportunity to break free from a medical discourse and facilitate the production of a home environment that can incorporate novel ways of being ill and alternative forms of care. Such care, if it is moral care, must give equal weighting to patients’ desires (whatever these may be) and biomedical discourses allowing and promoting (re)formations of the home and home care. If understood this way, ‘best practice’ as a discourse can be observed to be the antithesis to quality care when it precludes the (re)formation of the home as capable of producing care.

‘Severe’ illness

For other patients, illnesses may not be acute and sudden, but may prove too severe to be managed at home.

“P7: when the time comes… I'd be quite happy to have the district nurses… it depends how severe my illness is at the end… if I need a load of lifting and this, that and the other, I need a lot of support in doing, and it's affecting her [my wife], then I would rather be in hospital.”

In such statements no thought was given by patients or carers about whether district nursing services could alter or provide extra care to manage ‘severe’ illness at home. Instead, district nursing started to become unviable when faced with severe illness but for reasons that were unclear and unknowable. In addition no clear guidelines were even given regarding what care could be managed at home:

“P17: I think you've to sort of recognise a point where you can be cared at home and when you can’t be, you know. I think
that’s, I mean obviously I think you… if you’re poorly there is a line where I think, you know, you need to be in hospital and then a line where you can think right, no, I can probably come… home.”

The line that P17 talks about is not a clearly defined line, but its presence permeates his subjectivity and the subsequent viability of his home environment serving to legitimate inaction on behalf of the district nurse to maintain him at home. An emphasis is also placed on the patient to recognise and accept this line rather than reform and develop such a line in conjunction with district nurses. However, with a lack of power/knowledge it is unclear how any such reformation may take place. In a similar way to acute illness, severe illness serves to form a viable but restricted subjectivity of patients at home by precluding the homes reformation. This allows district nurses to direct patients away from the home/home care using extant (often biomedical) discourses rather than allowing and promoting a (re)forming and exceeding of discourses.

8.4.3 Moral production of severe and acute illness

There did exist one clear example of patients and carers engaging with district nurses in a way that could be considered moral (for clarity this interview was conducted jointly with C6 and P6 but was edited for brevity only leaving C6s comments):

C6: There is one district nurse comes out every few weeks to see him, but all the district nurses, we’ve got day and night if we need them. Like if he’s taken ill, he has his, you know, he has his nebuliser, he has oramorph [oral morphine], his oxygen. Now if none of them work that’s when we get the district nurses in to come and see him, but touch wood, that hasn’t happened as yet. They said it will eventually, but…
Interviewer: In what situations would you call the district nurses then or have you called the district nurses?

C6: If first of all I put him on his nebuliser, and then his oxygen, then the oramorph, now if none of them work that’s when I contact the district nurses and they will come, make him comfortable and sort him out, do whatever they have to do for him…he’s on palliative care, and everybody is involved within district nurses, community matron, heart failure nurse, everybody is involved, because he has had to sign a consent form to say that he doesn’t want to be in hospital, he wants to be at home.”

Within this patient-carer-nurse triad it is clear that what can be undertaken in the home has been discussed and facilitated by the district nurse and other healthcare professionals. However, despite wishes such as this being expressed limits are still placed on what are viable acts within the home:

“C6 She [district nurse] came one day and she said to me, [P9] looks ill this morning, but when you see him every day, you don’t see that straight away. I said, do you think so? She said yes, I’m getting him to hospital. She phoned the hospital, she said I don’t want him going to A & E, I want a bed on the assessment ward and it turned out he had got pneumonia… he has to have it [antibiotics] intravenous…he was in High dependency unit yes, he was so poorly with it.”

Therefore, whilst for P6/C6 the tasks that can be conducted in the home have been expanded to a certain extent, it is clear that there are still limits being placed on the treatment of certain illnesses and these limits are imposed through what the district nursing service is able and willing to provide curtailing patients’ choices and wishes.

Whilst illness is a necessary condition for district nursing care to enter the home, it must be the right ‘type’ of illness, generally (though not exclusively)
physical, pre-existing and predictable. Patients’ power/knowledge to expand the conditions of viability become very limited in that they are unable to alter their illness and in relation to home care viability they are offered little power to expand upon the extant discourses of district nursing care. Therefore, patients and carers generally are only able to have district nursing care in line with the extant discourses unless district nurses (re)form them. Patients are unable to perform this (re)formation because of the subjugation described in the previous two chapters. This produces an underlying yet hidden immorality to district nursing care, by precluding any reformation of home care in line with patients’ and carers’ desires; desires which become increasingly hidden and repressed within privileged extant discourses.

8.5 Affect\(^5\) of care on ‘the home’

Now that the viability of the home has been delimited and the discourses that produce and preclude its (re)formation have been explicated, one needs to question if what was meant by ‘the home’ remains the same. What affects, if any, does district nursing care have on the home? Nearly all patients declared that district nurses did not affect ‘the home’.

“Interviewer: Do you think district nurses coming in affects how your home feels?

P9: No.

Interviewer: No?

P9: No. Not in any way, shape or form, no. The dog barks. We’ve got to put him in the kitchen. We let him out and they

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\(^5\) The use of affect, as opposed to effect, is used to keep in agreement with the poststructuralist viewpoint of discourses and individuals being a series of flows and processes all interconnected and all interconnecting, unstable and constantly (re)forming. Therefore, at times the use of ‘affect’ in this thesis may appear erroneous, and many authors considering the sentence in isolation would opt for effect. However, this would be a misreading of the grammar outside of the poststructuralist philosophy argued for in chapter 2.
pat the dog and what-have-you when the excitement has died down."

This lack of affect on the home was sometimes qualified by patients and carers:

“Interviewer: I'm wondering how you feel about nurses coming into your home?

P20: Doesn't bother me anybody coming in to my home as long as I invite them in. If I invite them in and they respect the home when they come in that's no problem.”

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“P2: friendliness sort of stops it affecting how your home feels really.”

Qualifying the interaction with the district nurses in ways such as ‘inviting’ and ‘building friendships’ suggests that district nursing, in some ways, has potential to affect the home. Therefore, whilst patients have little power/knowledge over the viability of their home as a site of care; they may maintain some power over its affect.

Only P12 felt district nurses did affect the home:

“P12: anybody coming to your house that you don’t know is quite invasive. It is invasive no matter whether they’re coming in for good purposes or bad purposes really… Yeah. It’s not so much intrusion, it’s like sort of you want to get back to normality, et cetera, and somebody coming in like the district nurses are coming in because you’re not at a normal phase or
something, if that makes sense to you. So even though they’re a safe person coming in the sooner you can get rid of them the better.”

However, the case of P12 is unique in that she was now in remission from her cancer and was no longer receiving district nursing care, though there was the possibility of further post-operative care post-stoma reversals. Therefore, district nurses no longer served as a way to maintain her home. In this way she was able to critique the affect they had had on her home and the lack of normality district nurses represented without being reliant on them to maintain her home as a viable place for care.

There were however attempts made to eliminate the affects that district nurses had on the home through strategies that sequestered the district nurses’ physical presence to specific times and places

“P12: I used to get things ready for them [district nurses], I used to get the box out and the folder”

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“C7: they had a box with all their things in but that was really was about it.

Interviewer: Did you ever go into that box out of interest or was a just a bare box?

C7: No, no… even now we have the box on the small bedroom bed”

Intrusion into the home may therefore be masked by: the reliance patients have on district nurses to maintain their home and their subjectivities in relation to the home; and an ability for some patients to sequester away the district nursing affect on the home maintaining power over it by only opening
‘the box’ at pre-ordained times. However, intrusion as an idea continued to featured in some patients’ and carers’ accounts, but in relation to the home becoming an unviable place for care and being compelled to ‘accept’ the alternatives of hospital or nursing home care:

“C7: To me it would be more of an intrusion, P7 going in hospital, he wouldn’t want to go there…he wanted to stay at home.”

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“Interviewer: And would it matter if the district nurses were coming in more often, so three or four times a day?

P19: No.

Interviewer: It would matter that you were at home…

P19: Yes, that’s right, yes.

Interviewer: …than hospital.

P19: No, the district nurses could come in as many times as they want, because I’m with the family. It wouldn’t bother me.”

In this way whilst district nursing care may affect the home in ways that are difficult to assess, the effect still appears more moral than allowing the home to become unviable as a place of care. This begs the question of how patients should be given the choice of home care (if choice can be said to exist) and what boundaries can and should be morally placed on it. In order to move towards answering this, the affect that the home has on nursing care must also be considered.
8.6 Affect of ‘the home’ on care

There were a variety of ways in which care was altered by virtue of being in the home environment. In the case of IV therapies this was a ‘presumed’ difference because no patients had received IVs at home limiting analysis in this area. However, all the other areas examined such as psychological care clearly demonstrate how ‘the home’ alters the care that can and does occur between patient, carer and nurse.

8.6.1 IV care

IV therapies continue to be a fertile ground for critique as whilst care may at first appear equivalent (i.e. similar drugs are given) the interaction of the home on IV services is potentially transformative for the experience of care:

“P14: there is supposed to be an IV service set up and the district nurses are supposed to be going to do the evening ones I think…. it would be alot better if I could have them at home rather than at hospital, because you’d probably get it at a better time, you wouldn’t have the chance of picking up another infection, and you can do things at your own pace at home, where if you’re on a medical ward, you know, it’s like yourself, it’s midnight before you’re getting your ten o’clock IVs and then six o’clock when you’re getting your next lot. So hoping with an IV service it won’t be that, I can manage it better. Plus it’s less stressful if you’re at home.”

The home appears to have the potential to ameliorate the loss of independence associated with and at times expected with illness and hospital care. However this can only be achieved if boundaries of what ‘the home’ can contain are allowed to reform. However, often such boundaries do not appear to be controlled by patients and carers; instead patients are unable to think beyond the extant discourses performed by the district nurses:
“Interviewer: Is there anything extra that...So I suppose in an ideal world, not necessarily they do now, or you can see them doing, but is there anything in an ideal world that you think district nurses could do to help keep you out of hospital?

P19: I don't know, not sure. I can only think of if, that they come to see, I don't know, I'm not sure, I don't know.

Interviewer: I mean one thing that a previous person mentioned is giving IV medications.

P19: Oh right.

Interviewer: Now I'm wondering how you feel about that being done at home rather than hospital?

P19: Yes, I'd rather have that done at home, yes.”

Whilst this form of questioning could be considered as ‘leading’ it is important to reject such notions. Instead, this form of questioning was aimed at examining how patients were able to think about their district nursing service in relation to the home, examining how novel suggestions outside of their current discursive regime were received. In this case, it appears that the extant discourses are restricting thinking away from IV therapies even though once mentioned P19 was relatively enthusiastic about that possibility. Therefore, if the boundaries of what can be done at home are to be reformed, the discursive regimes that district nurses function under also need to be expanded and open to challenge.

8.6.2 Psychological care

The home may also serve to alter how psychological care is carried out between patients and nurses:
“P12: I was at home after my operation and obviously my kids and things were coming in and looking after me, but I think for them [district nurses] to recognise that hang on a minute, this is not just somebody being down after an operation. You know, it’s not the GP that’s coming calling.”

For P12 and many other patients, the regular home visits, often weekly to monthly occurring after physical care needs had finished were valuable and reassuring, even if no particular task were undertaken:

“C21: they’re [district nurses] going to come weekly now. She said she would come, I think it’s Thursdays she’s going to come, every Thursday to see him. Which will be good… and make sure he’s okay.”

Psychological care, whilst something healthcare professionals are often instructed to undertake regardless of context, appears to be facilitate by the home:

“P14: because she was doing the portacath, setting up. I usually have everything ready set up, you know, the tray out and…and I got it out and she just looked and are you not knitting? Because usually my knitting’s out in the day…and I said no, I’m a bit…are you alright, you know, are you not so good? And then I just said I’m fed up, you know.”

By virtue of care occurring in the home, the nurse was able to note changes in the home environment and attach significance to them. Whilst psychological care occurs in other settings it appears the home and the geography that the home affords is a facilitating factor. These cues are too wide and varied and individual in nature to document in any detail from this study and in themselves may merit further research. However, their presence in the home appears to facilitate care when required.
8.6.3 Feeling of home care

Whilst specific aspects of care such as IV medications and psychological care are perceived as being affected by being conducted at home, a more general comment can be made about how care feels different and is altered when it’s conducted at home:

“P14: when you’re in hospital you’re waiting all the time for somebody to do. If you want to go to the bathroom, if you want a drink…if you’re in your own environment I’m hoping that I’ll be able to get to the bathroom myself without having to wait for a commode, or at least it’s near enough to get to without being at the other end of the ward. If you want a drink you can get a drink. You can have your meals when you want them…you’ve not got that moving beds at two o’clock in the morning and things like that. You know, you get better. You can sleep better as well in your own home.”

In a similar way to IV care at home, the home has the potential to alter the overall experience of care in a positive way by restructuring a whole variety of tasks. Such a reformation of care is not however only limited to a hospital versus home dichotomy. This was particularly well demonstrated by one patient who whilst receiving the same injection when the location varied from the home to the district nursing clinic his experience of the care altered:

“P16: At first it was, they were quite friendly and chatty. But when I started going there [district nursing clinic], I’m now just a patient… Just one on the list.”

For P16 it was the home that altered the care, even though it was the same nurses and the same injections. ‘The clinic’ converted him into a non-identity, just one on the list. Therefore, the home may produce a more personalised and individual framework for care which is viable in both the home and the hospital.
8.7 Affect of home care on patients and carers

Whist the home affects care and care affects the home, these reformations also have an affect on the patients and carers themselves through maintaining and reforming the conditions of subjectivity in a variety of ways. Two of the most influential factors are documented here: social lives and signification of the home. Data from a carer perspective is too limited to allow a detailed discussion of how it may differ. However, the limited data suggests that there may be different effects which are briefly described at the end of this section.

8.7.1 Social

In addition to the altered way that nurses interact with the home, care at home also allowed existing social support and lives to be continued:

“Interviewer: So what is it about being at home then instead of in hospital for you?

P19: Well, you're next to your family, because a lot of time the family can't get to hospital and what not, especially the little lad [my son]. I spent a lot of time in hospital and he wasn't allowed to come and see me, because they've had a lot of this bird flu and stuff like this at hospital, and... So yes, I'd rather spend my time at home with the family than in hospital with a load of strangers.

Interviewer: And would it matter if the district nurses were coming in more often, so three or four times a day?

P19: No.

Interviewer: It would matter that you were at home...

P19: Yes, that's right, yes.
Interviewer: …than hospital.

P19: No, the district nurses could come in as many times as they want, because I'm with the family. It wouldn't bother me.”

For other participants the home represented a lack of social interaction, but this should not to be read as a negative experience:

“P18: I'm particularly happy with the situation that's happening now where they're talking about elderly people being cared for in the home… I'm being treated in my own home and, as I've said to you before, I can't…I can't say anything at all about the service I've got because it's been absolutely marvellous.

Interviewer: Does it change the feeling of your home at all?

P18: Well, obviously, people coming into my home now but, on the other hand, the way I am, I've got a few friends around me but the weeks are very, very quiet… They say, a lot of people, it would be lovely for an old person to sit in the corner and go and talk with the pink rinse ladies and have a game of whist and all that, but I'm not that type of person, I'm just not that type of person… I'm glad they [district nurses] are coming in, and I'm glad they're looking after me, obviously! Because, otherwise, there wouldn't be anybody, would there? I'd be in hospital, in other words, I'd have to be somewhere, or a nursing home, or whatever.”

Examining both these cases together, it becomes apparent that home care becomes valued when it maintains a desirable social life for the patient. Whether this be one full of family and visits or a more quiet one, the morality in this can be seen in the (re)forming of how a social life may be maintained rather than reforming the social life itself.
8.7.2 Signification of the home

The home however, was not only a site of care, but was a site of creating identity for patients and carers facilitating the continued performance of patients and carers *subjectivities*:

“P21: Being away [from home] is not a nice experience, certainly not the one that I went through, but being at home is absolutely vital.

*Interviewer:* Yeah. So how important are the district nurses in keeping you at home then?

*P21:* You know, well, they're vital”

“C15: it was a lot of talk at the hospital…in fact they suggested that he [P15] might go into a nursing home. And we said no, because it would have finished him off”

Without this site of identity it was felt that patients would literally be finished off; the boundaries between social body and physical bodies in patients’ and carers’ representations were far from distinct and the ways therefore in which the home not only maintained social but bodily existence appear inextricably tied. Such speech echoes the work of Deleuze and Guattari (Deleuze and Guattari 1988, 2004) who question the Cartesian separation of mind and body and instead view the body as having no physical and natural content, instead being entirely socially inscribed by discourse. If understood this way, the vitality of the home can be better understood as formative and sustaining in just the same way as food or water would be to one’s being.
8.7.3 Effects of home care on the carer

The effects of home care on the carer, whilst at times positive, were often only positive in a vicarious way through the patient, i.e. helping to fulfil their loved one’s wishes. Whilst this never appeared to be resented, it was at times a source of stress:

“C17: No, I'm sick of folk keep coming… I never get my housework because there’s everybody coming.”

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“C15: I think the hard part was, when he came home for the first time, and it was knowing who was responsible for ordering things… district nurses are responsible for some things and your doctor is responsible for other things… it was quite a stressful time really.”

Whilst further theorisation is limited because of the lack of carers interviewed. It can tentatively be suggested that there are aspects to home care that produce stress for carers. These factors appear not to be with the care of the patient as such but instead are to do with how the home is affected and care organised in ways that are outside the control of the carer.

8.8 Summary: dialectics of ‘the home’

That ‘the home’ is so meaningful for both patients and carers, and that district nurses become ‘vital’ in maintaining it suggests a linking of the home, the patient/carer dyad and district nurses. However, when such a link is examined within Butlerian framework it becomes apparent that it is more than just a linear relationship. Instead both ‘the home’ and ‘care’ affect and build each
other up in a dialectic way and the home becomes a vital sustaining component of one’s subjectivity.

There are examples of how district nurses acted to protect and maintain the home. This has been demonstrated to be of great value to patients and carers who (re)form their subjectivities at least in part in reference to the home. However, many of the ways in which the home were maintained and (re)formed remained either outside of the power/knowledge of patients and carers (such as IV fluids), or relied on the patients’ health which patients had little to no influence over. Much of the immorality of this appeared to stem from the privileging of ‘best practices’ in line with biomedical discourses over discourses such as the importance of the home or family.

The following discussion chapter will begin to problematise how patients can be involved in resistance to power/knowledge and theorise ways in which moral care can be produced within contemporary home care settings.
Chapter 9

Discussion

9.1 Introduction

9.1.1 Summary of research question

The aim of this study was to explore patients’ and carers’ views of quality palliative and supportive district nursing care. This arose in three different ways. Firstly, research primarily addresses quality of palliative and supportive care from healthcare professionals’ or funders perspectives, with less research addressing patients’ views. Secondly, Government policy claims to seek the involvement of patient and carer views into healthcare policy and practice. Thirdly, the research that begins to address patients’ and carers’ views (reviewed in chapter three) lacks an understanding of what frames patients’ and carers’ thinking on quality of care and how it may be (re)formed and restrained by other discourses. Therefore, this thesis explores what patients’ and carers’ views were, and why they thought this way. Then, in line with post-structuralist methods examines what barriers prevent patients’ and carers’ views (re)forming and being incorporated into healthcare policy and practice.

9.1.2 Discussion chapter use of literature: becoming-rhizomatic

To explore the research questions post-structural theory (primarily but not exclusively Butler) was used to theorise an understanding of quality care as moral care. When coupled with discourse analysis techniques, a way of approaching empirical data was developed which allowed an exploration of what formed patients and carers subjectivities and what framed their thinking. This resulted in three findings chapters that explored the framing of quality care: busyness, knowledge, and maintaining the home.
This discussion chapter takes the previous three chapters and their themes and considers how busyness, knowledge and ‘the home’ may produce or preclude quality care. The three themes main function is to act as a starting point for reference to a wide range of social science and humanities literature. The aim is not to examine whether patients’ and carers’ commentaries confirm or refute theoretical constructs in other disciplines. As Foucault suggests:

“If you recognise the right of a piece of empirical research, some fragment of history, to challenge the transcendental dimension, then you have already ceded the main point… to free history from the grip of phenomenology.” (Foucault 2002: 224)

For Foucault, empirical research into the experience of the living cannot be used alone to produce challenging analyses of the lived experience because it is constantly produced and restrained by itself. Instead, experience should be problematised and analysed with abstraction and theory. However, this poses the problem of what theory and what literature should be used to produce this abstraction. Deleuze and Guattari suggest a philosophical approach to writing which helps an author to produce challenging analyses:

“A book has neither object nor subject… to attribute the book subject is to overlook this working of matters, and the exteriority of their relations… when one writes, the only question is which other machine the literary machine can be plugged into, must be plugged into in order to work… There are no points or positions.” (Deleuze and Guattari 1988: 4-9)

Deleuze and Guattari (1988) in their chapter Rhizome lay out a way of understanding knowledge as without “points or positions”. Instead they encourage writing to be rhizomatic, engaging with texts that produce new ways of understanding. They contrast this with an arborescent (modernist) form of knowledge which builds on texts in a hierarchical way, containing knowledge within its pre-existing structures and ways producing ‘new’ knowledge, but within existing disciplinary frameworks. Therefore within this discussion chapter, whilst the genesis of the research question in the
introduction chapter was grounded in nursing literature, no automatic privilege is given to nursing literature in the discussion chapter. Instead literature is “plugged into” that produces new ways of thinking; literature that does not challenge and produce new ways of thinking and instead reproduces a hegemony is not used.

9.1.3 Tensions in the utility of a discussion chapter

There remains a tension when using post-structuralist techniques in empirical research. Challenging ideas to break down hegemonies by thinking counter-intuitively and rhizomatically with theory and texts; opening up possibilities for new subjective positions to be taken up; and applying this thought to immediate and pressing situations to achieve a positive social change (positive as defined by the power gained through academic discourse), possibly closing down opportunities for the (re)formation of subjectivities by producing conclusions and ‘truths’.

Having taken time and energy from patients and carers I personally feel an ethical call (a call I do not feel on an academic level where empirical data derived from participants is not being used) to do more than just question hegemonies hoping that they will be broken down, reformed and changed somehow; it is a call to ‘make a difference’ (as so many of the participants hoped to with their participation) in some (even slightly) tangible way. However, academically the call to abstraction also needs answering. As Butler puts forward:

“Scholars are obliged to question common sense, interrogate its tacit presumptions and provoke new ways of looking at a familiar world… If common sense sometimes preserves the social status quo, and that status quo sometimes treats unjust social hierarchies as natural, it makes good sense on such occasions to find ways of challenging common sense.” (Butler 1999: emphasis added)

This chapter includes theoretical discussions that whilst having their seed in empirical data, have no clear tangible benefit to patients and carers, instead
aiming to explore post-structuralisms strengths and weaknesses and theorise new ways of understanding not always related directly to district nursing but producing a ‘new way of thinking’ about the ‘familiar world’ of district nursing. If keeping true to post-structuralist philosophies this is the only way in which hierarchies can be challenged, by posing questions and developing theory which gives no single clear answer but instead multiplies possibilities.

Therefore, this discussion chapter is a production of tension: a desire for academic abstraction to question but not conclude about hierarchies, *hegemonies*, and *power/knowledge*; and an ethical call to produce something of tangible use from empirical data for research participants. Some aspects of this work do not provide or even attempt to provide answers, they raise questions about the empirical data and develop theory around the themes, thinking in new ways about them; others resolutely do attempt to produce answers, using empirical but interjecting theory to develop ideas from the empirical data in an ultimately utilitarian manner. In this tension novel ideas will be developed around how discourse functions within district nursing, and the limitations of post-structural theory in relation this study will be critiqued.

There are then two possible ways that the empirical data can be used to ‘make a difference’ and related to practice. They could be written in relation to a radical theoretical/political framework, relatively disparate from the current frameworks that district nursing operates in, attempting to completely re-write district nursing. Whilst this is a valid aim, it is unlikely to produce much of the ‘making a difference’ in the short term that I feel an ethical call to address. The other way that implications for practice could be addressed is within the current political and philosophical frameworks highlighted in the introduction, namely neoliberalism examining how it can be reworked to produce quality of care.

9.1.4 Neoliberalism and quality of district nursing care

In making this decision it is necessary to consider to what extent district nursing and palliative and supportive care are already effected by neoliberal reforms, and therefore how productive writing this chapter of the thesis in
relation to neoliberalism would be. Until now in policy terms, district nursing services have remained on the sidelines of neoliberal reforms; neither markets nor choice exist within district nursing services. This does not however mean that neoliberalism has no effect on district nursing services. For example, other ways of ‘increasing efficiency’ have occurred in district nursing such as removing responsibilities for social/personal care (washing, dressing) alongside an increase in healthcare assistants carrying out tasks such as dressings and catheterisations (QNI 2011). There has also been a clearly documented fall in the number of district nurses and a redirection of district nurses to more ‘complex’ cases (QNI 2011). Therefore, whilst healthcare markets do not fully exist for district nursing services (though neoliberal philosophies are increasingly being applied to the service as a whole); when considering the pace of change in the NHS and the increasing drive for ‘efficiency savings’ via the involvement of private companies in healthcare provision (Great Britain 2012) it is possible district nursing may be more directly affected by these reforms in the future.

Whilst district nursing services have no history of having alternative providers of care, the same is not true of palliative and supportive care services which have a long history of having non-NHS ‘willing providers’ in the form of charitable services. However, in general these providers have not been run along neoliberal lines, instead receiving block grants (Hughes-Hallet et al. 2011). Whilst there are moves to reform the funding of palliative care provision to introduce a per-patient tariff based system as with other areas of healthcare (Hughes-Hallet et al. 2011), such arrangements are not currently in place.

Therefore, neither district nursing nor palliative care can truly be considered to be operated in a fully neoliberal way, but both remain affected by neoliberalism. District nursing because there are no other willing providers who are providing a full range of district nursing services in competition with current NHS district nurses, and palliative and supportive care because there are few market structures providing competition. However, if current reforms and proposals continue on their current path this may change in coming years. Therefore, it is within this overall political context of neoliberal approaches becoming increasingly influential in palliative and supportive care and district
nursing that a decision is made to discuss the findings of this chapter, and suggest implications for practice, in relation to neoliberalism. By doing this, it is hoped that some difference can be made in areas where neoliberalism is not as advanced as in other areas of healthcare offering a chance for alternative paths to be pursued.

However, as with all research, the suggestions that can be made are limited by the conditions within which the research took place. Therefore, a discussion of the limits that formed this thesis is necessary to ensure rigorous conclusions are drawn out.

9.2 Limits

There are many limits to this study. To preface this argument, these are not considered to be strengths and limitations, to do so may suggest that the arguments put forward in this thesis can claim to be stronger or weaker than other arguments, they are not. Instead, they are put forward to make clear the specific conditions which do as much to produce this research as the act of writing does by framing what may or may not be writeable. Therefore, a detailed account of what limits this thesis is beneficial to frame the subsequent discussion and understand the conditions that produce the thesis. A discussion of strengths does not carry with it the same necessity nor would it have the same effect. Therefore, there is no explicit discussion of ‘strengths’.

9.2.1 Sample limits

Whilst at times sampling and recruitment was difficult, it was felt that a sufficient number of participants were recruited to give a broad view of district nursing from the patient’s perspective. There were however, limits to the sample. Whilst not aiming for a representative sample percentage wise of diagnoses, it was felt that patients with a non-cancer diagnosis were still under represented in the sample. This stands as one of the key limits imposed by the sample. Absent in this sample were any self-identifying lesbian, gay, bisexual, and transgender (LGBT) couples or individuals, or working class individuals. Black and ethnic minorities (BME) were also under-represented with only two
participants (P23) being from a BME community. These are all factors which are known to affect access to palliative care services (Kessler et al. 2005; Koffman et al. 2007; Almack et al. 2010). However, without access to the caseload demographics and knowing who was or was not offered an opportunity to be involved in research it is difficult to assess the reasons for omissions in this research project. However, having worked in two of the primary care trusts for a hospice at home service I was aware that there were generally patients with the above characteristics, who had contact with district nurses but remained unrepresented in my sample. A larger and more diverse study sample may help explore how different demographics effect the interaction on a moral level with district nursing services. Future research may wish to address in more detail specific social and demographic groups’ views on quality in palliative and supportive district nursing care.

9.2.2 Ethical limits

The ethical limits that produced this project were highly specified and were probably the most influential discursive framework. Whilst there is clearly an ethical imperative to ‘do no harm’ for anyone who enters into research, the ways in which this is achieved impact on the production of research. The separation of researcher from participants via other healthcare professionals places particular limitations on recruiting participants. Not only does it rely on the pragmatics of healthcare professionals remembering to hand out packs, but it also raises questions about who healthcare professionals thought were suitable to take part in research. For example, it seems unlikely that patients and carers who had put in formal complaints would be offered to take part in a research project by those being researched (district nurses). This problem was realised at the inception of the study, and recruitment strategies were formulated that allowed more than just district nurses to recruit. However, it still remained impossible to access any information about district nursing caseloads (a limitation placed on the researcher by the research ethics committee) to make some judgement about whether particular groups of patients and carers were being excluded from the research. The researcher was also disallowed any information on who had been offered to take part in
the research but had declined. The limits relating to sample recruitment remain largely unaccountable for in the research.

Examining the demographic details in appendix J it appears that the sample is disproportionately white (only P23 and P1 were from ethnic minorities), heterosexual, middle class, and with a cancer diagnosis. Whilst a statistical form of representativeness wasn’t being aimed for in this study, it is possible that a sample with different characteristics would face different barriers and facilitators to accessing and (re)forming their subjectivities. For example, it may be possible that class and/or race require different support and would interact with their district nursing services in different ways, something described in other healthcare research (Kawachi et al. 2005) but due to this projects homogeneity it is difficult to make any suggestions about a variety of identities and demographics may influence the data.

Accessing patients with non-cancer diagnoses, whilst successful was limited. Again, because of an inability to access district nursing caseloads, it is not known whether this is because as suggested by Exley et al (2005) and Burt et al (2010) that non-cancer patients have less contact with district nurses even when matching for symptoms, or whether it was because district nurses were less willing to discuss palliative and supportive care with non-cancer patients. Whilst Exley et al (2005) and Selman (Selman et al. 2007) both suggest that non-cancer patients may have different levels of awareness regarding prognosis, there is no explanation as to why there may be different levels of awareness. Within this research project, patients who did have a non-cancer diagnosis showed no discernible difference in levels of awareness. The experience of the researcher suggests that the reticence that many district nurses had in discussing the study with non-cancer patients may in itself produce an apparent lack of awareness similar to Glaser and Strauss’s (1966) mutual pretence awareness where both parties know but fail to acknowledge the palliative nature of an illness. Therefore, it is tentatively suggested that it is not as much patients’ awareness that results in lack of participation in research but more healthcare professionals’ reticence about discussing palliative and supportive care with non-cancer patients. The extent to which this and other
factors factor into the underrepresentation of non-cancer patients and carers would benefit from detailed research in itself.

9.2.3 Limits of interview methods

Whilst interviews were semi-structured and didn’t follow any formal structure there were formal procedures that ethics committees required of the researcher before interviews could commence. Ideas of informed consent required that participants were presented with an information sheet clearly describing the project and its aims. NHS ethics committees provide guidance for such information sheets and this guidance was followed regarding content. However, other areas of academic research have radically different approaches to ‘informed’ consent and may not even seek it either initially or at all for ethnographic studies (Lawton 2000; Dean 2009). Why then are ‘patients’ and ‘carers’ considered special? Some have argued that because patients and carers (especially those with palliative and supportive care needs) are ill, then they are vulnerable to being coerced into taking part in research, arguing that structures need to be in place to separate the researcher from the researched (Bruera 1994; Addington-Hall 2002; Dean and McClement 2002). Putting aside the arguments for and against this, it needs to be considered how this frames the researcher and the researched. Identities are created (as much as they may be resisted) through the language used in produced information leaflet: “research study”, “I am an experienced nurse”, “this study will be kept confidential”, “anonymised quotations” and either “patient information leaflet” or “carer information leaflet”. The researcher becomes a nurse-researcher, both of which come with significant power/knowledge and participants are interpellated as patients and carers who are denied any identity in the final research paper beyond anonymised demographic data, codes and quotes.

Such an approach to the researcher ‘using’ the participant’s data seemed to produce a hierarchy between researcher and participant:

“Interviewer: So if you want to tell me a bit about yourself

P12: What do you want to know? I mean…

____________________________________
Interviewer: Well, I suppose it’s interesting for me to know a little bit about your background, so what sort of work you do and did."

The control of the research was therefore both explicitly and implicitly within the researcher’s domain; literally it was what I as the researcher “wanted to know” that lead the interviews, despite at times trying to offer very open ended questions, context and limits were required to produce the texts. This point withstanding it is also likely that participants to some extent either gave answers that they felt the researcher wanted to hear, withheld information that they felt was controversial (i.e. illegal activities), or only spoke what was speakable within the discourses available to them. This limits the study as being a ‘true’ representation of patients and carers views on quality palliative and supportive care instead transforming it into a representation of representations. In other words, as a researcher, I am representing views which are representations themselves put forward by district nurses. As all representations occur within language and viable social discourses, the arguments put forward here have been doubly restricted.

Data collection strategies also limit some of the later conclusions in this study. That the research study was entirely based on interview data precluded certain analysis. Once research interviews had concluded and analysis in the context of much broader literature began it became apparent that the materiality of the home may contribute to patients’ and carers’ experiences of district nursing care (discussed later in this chapter). Whilst small amounts of data were gathered through patients’ comments about their home, a more systematic approach to recording the material conditions of the research was not undertaken limiting the later conclusions put forward in this chapter about the materiality of the home.
9.2.4 Social limits

Whilst it was difficult to assess how true this was for participants, it is likely that at least some participants felt cautious about speaking frankly about their district nurses when it was the district nurses who were maintaining them at home (something highly desirable for patients as discussed in chapter 8). There is limited evidence for this in the way that P7 ‘corrected’ himself when discussing district nursing care. However, there was no overt acknowledgement of censorship. Therefore, whilst participants may have ‘held back’, the extent of this holding back is difficult to assess with empirical data. Nonetheless there do remain examples of participants critiquing their district nursing service, or to a lesser extent highlighting the limits of their care and exploring what they would prefer.

9.2.5 Pushing limitations with theory

The development of theory has served as a particular way of pushing the limitations of current thinking around how quality of care and district nursing have been conceptualised. Post-structuralist theory has also influenced the general approach to analysis challenging by encouraging the linking of disparate texts outside of the traditional ‘health services research’. This has helped produce a wide, varied and novel analysis. Whilst still intrinsically limited (as all things must have limits) it is felt that this analysis of ‘quality of care’ has developed and pushed back the limitations of previous thinking opening up new avenues of academic enquiry.

Whilst I had limited knowledge of post-structuralist theories prior to data collection, this knowledge developed and began to influence data collection and data analysis. This is not problematic; instead, my lack of grounding enabled me to reach out and access texts when needed, appropriating them in ways that were beneficial to the research project when needed. This is relatively in keeping with interpretive traditions in qualitative research with seasoned researchers encouraging neophyte researchers to somewhat ‘just go and do it’ (Glaser 1998; Charmaz 2006; Bryant and Charmaz 2010).
This thesis can be considered a starting point, not a conclusion, for the interaction of a wide array of theoretical ideas in relation to quality of care. Additional data and theory can continue to develop what has been an already fruitful process and future work can build on examining quality care as moral care as laid out in chapter 2. However, future work must also continue to reconceptualise the ‘quality of care’ itself just as this study has, using challenging and disparate theoretical ideas further pushing at the limits of the debate around quality of care. Therefore, whilst this thesis has had to draw limits on what it considers quality of care to be, these ideas should not continue to limit future work.

9.3 Busyness

In chapter 6 busyness was explored as one of the key discourses that restricts patients and carers subjectivities and precludes moral care. Alternative discourses were explored for how they produced moral nursing care such as ‘friendship’ and ‘becoming-younger’. In order to theorise ways moral care can be produced it is particularly important to examine busyness, due to its all pervasive nature in the data produced about district nursing in this project.

Within current political ideologies explicated at the beginning of this chapter, one needs to question whether, and if so how neoliberal policies operate in tandem with busyness to produce or preclude moral actions. Increasing efficiency has been suggested to produce a form of ‘social acceleration’, where technologies decrease the time taken for essential tasks (such as cooking, eating and washing) and increases the amount of time available for economically productive tasks (such as the mobile phone creating an always available worker) and has been suggested as a factor that contributes to the production of busyness in everyday life (Robinson and Godbey 2005). It is suggested that this feeling of social acceleration occurs through capitalism’s desire to produce new and more efficient means of producing more labour for less money (Harvey and Braun 1996). Competition is a key factor in producing this social acceleration by placing providers against one another in market
situations to increase the pressures to produce more for less; potentially making one provider economically unviable, something undesirable in a capitalist framework (Scheuerman 2005). Social acceleration and the subsequent busyness that is produced has been examined for how they produce and (re)form multiple areas such as domestic life (Darrah 2007), work life (Gershuny 2005) and political activism (Scheuerman 2005). Whilst busyness is often acknowledged in healthcare as a problem (Evans 2006; Radcliffe 2010) analysis has not focussed on how it (re)forms the subjects involved in healthcare and what this (re)formation means in moral terms.

Whilst opposing concepts like ‘wastefulness’, ‘inefficiency’ and ‘slowness’ appear undesirable qualities, they remain subjective and require analysis to explore what and why certain actions are considered efficient (viable within capitalist frameworks) or inefficient (unviable within capitalist frameworks). For example, efficiency in district nursing becomes contested when tasks such as lighting fires and cleaning are done (Speed and Luker 2004) yet remains uncontested in relation to acts such a leg ulcer dressings. Criticism may occur of district nurses for not instigating ‘best practice’ (Royal College of Nursing 2011) however, this is not commensurate with the viability of a district nursing act itself; whilst dressing a leg ulcer poorly could be considered an unviable (and hence inefficient) act, it is not the dressing of the leg ulcer that is being considered unviable, it is the way it has been conducted in contradiction to best practice guidelines.

When examining this problem with the empirical data in the project it was tasks that were considered unviable, the manner in which tasks were carried out did not have the same effect. Therefore, becoming friends was thought of as an unviable use of time, whilst poorly dressing leg ulcers was accepted as viable yet undesirable care. Whilst it is clear that not all nurses abide by the restrictions placed on their practice, (Speed and Luker 2004) with efficiency becoming increasingly pervasive and considered desirable on a societal level (Cross 1993) to be considered to be carrying out intrinsically unviable acts (such as becoming friends), rather than just viable acts in undesirable ways (such as poorly doing wound dressing, a frequently cited reason for district nursing involvement by the participants in this study) risks ones identity within
a capitalist framework more than poor care alone would. To put it another way, poor care which has recourse to but fails to follow best practice guidelines remains discursively viable by performing in relation to discourses, in this case best practice guidelines; the following or not of these guidelines is irrelevant to its viability as a task. However, care which has no recourse to best practice guidelines because the underlying task itself is unviable, is automatically discursively unviable and within the neoliberal framework of modern healthcare is rendered inefficient.

The empirical data suggests that the only way to perform such tasks and remain efficient within the culture of district nursing becomes to perform them alongside viable acts. This desire for efficiency was reflected in the interviews by patients reporting that district nurses interweaved physical tasks with ‘slow’ actions such as counselling and befriending; something that research on ‘measuring’ quality of district nursing has ignored (Horrocks et al. 2012). The data also tentatively suggests that these ‘slow’ tasks (such as befriending which creates a space for subjectivities to reform) need not take a long time. The case of C3 demonstrates that merely addressing the carer and asking how they are is appreciated and opens up possibilities for his subjectivity to be reformed.

There is also silence in the data on other ‘slow’ tasks which literature suggests are beneficial to patients and carers with palliative and supportive care needs such as aromatherapy and relaxation techniques (Wilkinson, Aldridge et al. 1999; Kohara et al. 2004; Sood et al. 2007). This silence demonstrates how the ideas of busyness and a drive for ‘efficiency’ draw limits on what are performable and thinkable acts for district nurses. This suggests that broader socio-political ideology shapes what are viable district nursing actions and what quality care can be rather than research ‘evidence’.

9.3.1 What of choice to drive quality?

Within the wider political setup of neoliberal forms of healthcare, it is argued that individuals who experience poor care are able to choose an alternative
provider producing better quality care for that individual. Therefore, could extending choice within district nursing care be the solution to producing quality in district nursing care where the data shows that there is currently a relative lack of choice, or could choice further serve to restrict patients and carers subjectivities? To make an argument about whether ‘choice’ can produce quality in district nursing two questions need answering: in what ways do the ideas of producing measures to drive quality come to reform patients and carers subjectivities; and what moral effects does measurement have?

If choice is to function in a market to produce quality, information must be produced which allows choices to be made one way or another (Saltman and von Otter 1987; McGregor 2001). Within community palliative care there have been attempts to produce such information about district nursing services by producing standardised ways of measuring quality (Hirdes et al. 2004; Horrocks et al. 2012). Examining the internal logic of these various tools, what they regard to be quality care such as pain control and preventing social isolation are laudable. However, in an effort to account more fully for time and money a desire arises for measuring quality in standardised ways to compare services:

“[In] every sector of the healthcare system, efforts are underway to improve quality of care provided, increase cost-effectiveness… best practice and enhance public accountability…To evaluate the effectiveness of interventions by home care agencies at these potential turning points, it would be helpful to have standardized performance measures to document changes in client characteristics that can be compared between agencies” (Hirdes et al. 2004: 665 - 667)

This produces a market economy rather than merely providing guidance for professionals. In addition ‘choice’ must produce measurements. Such measures will then begin to reform patients and carers subjectivities in line with
the discourses expressed within the measurements, by making certain district nursing actions economically unviable by virtue of being immeasurable within the instigated framework being used to measure.

Therefore, choice appears not to produce quality for a whole system (though it may for the individual) and instead produces a system of measurement which forces the care of patients and carers to be increasingly measurable, and hence more clearly delimits viable and unviable care. As reflected in the empirical data care which is outside of measurement becomes unviable and unrepresented yet a pseudo-quality is maintained through producing docile patient-carer subjects. Further measurement in district nursing to facilitate choice would further entrench the inability of patients and carers to (re)form their care (as seen in the empirical data) and would further fix and curtail the possibility of moral nursing care where patients and carers can become-other and (re)form their care. Choice would also fail to operate on actions such as developing friendships (something many patients felt contributed to quality care) because befriending is unrepresented and unrepresentable within a neoliberal framework which prizes efficiency within biomedical frameworks for district nurses.

If ‘quality’ is thought of in terms of a post-structuralist morality which aims to multiply subjective possibilities, quality must become something which cannot be and is not measured because measurement immediately begins to erode the quality that it measures. Therefore, choice or any other way of attempting to direct practice so that it can be measured must be rejected as a path to quality. This is not to say that guidelines such as those for pain management or leg ulcers should not be used to guide clinical treatment; indeed, that is the very thing that they should be used for. However, ‘best practice’ should not be used to define and measure quality of care as suggested by many authors (Donabedian 1966, 1979; Brook et al. 2000; Campbell et al. 2000) as it will restrict subjectivities precluding the (re)formation of district nurses by the discourses described by patients and carers: developing friendships, making people feel younger and counselling; making these moral actions unviable preventing the production of moral and hence quality care.
9.3.2 The reduction of busyness

Busyness will undoubtedly remain to some extent as eliminating it entirely is implausible. What then is the solution to reduce busyness within healthcare and increase the quality of care given? In the literature review it was suggested that following Cheek’s (2000) philosophy of incorporating ‘alternative’ ways of thinking about nursing as ‘complementary’ would help incorporate alternative ways of measuring as put forward by Oudshoorn et al (2007b). This would result in incorporating building relationships alongside more biomedical measures. However this does not remove the problems of how ‘measuring’ and ‘choosing’ operate (regardless of what they are measuring and choosing) to produce busyness as a discourse that permeates district nursing.

Current policies and literature appear to suggest that introducing choice and measurement in district nursing is a distinct possibility (Darzi 2009; Department of Health 2010b; Davies et al. 2011). However, it is this exact philosophy that this thesis is arguing against. This thesis has developed the argument that measuring produces busyness and therefore precludes quality of care. Therefore, an alternative understanding must be put forward; if choice and measuring are removed from healthcare policies, then quality in healthcare would then be represented (importantly not measured) by patients and carers relating to district nurses in new and novel ways, reshaping and reforming their identities in novel ways blurring the identities of all parties involved. The antithesis of quality would become its measurement. McWilliam et al (2008) put forward a similar argument, suggesting ‘just being’ with patients should be allowed, but this does not account for what that being should be. As has been made clear by poststructuralists being cannot be devoid of discourse, one cannot just be without doing (or to use Butlers word performing); instead, as Butler has so keenly pointed out one must constantly repeat and perform discourses to be viable (Butler 1993, 1990). If nurses did attempt to ‘just be’ then they would rightly be criticised be being unviable. Therefore, the only way forward for quality is not ‘just being’ but instead expanding what being can be. The empirical data has suggested ways in which this may be done such as performing discourses of friendships, counselling and youth but this empirical
evidence should not be used to limit the ways in which this becoming-other can be achieved. Instead it should be used as an example for how moral district nursing may occur when a philosophical framework of becoming-other is applied to district nursing.

This approach does not exclude the use of best practice guidelines. These can continue to be produced and used but by not making them commensurate with quality it allows the instigation of best practice guidelines to be (re)formed in reaction to patients and carers without the ‘quality’ of a service appearing to be reduced when they are not followed; guidelines may once again become guidelines rather than protocols which must be followed and measured to produce quality care. By removing any form of measurement then, patients and carers will be freer to engage in a moral relationship with their district nurses. However, whilst reducing busyness and its component parts is important in producing moral district nursing, there remains the problem of how patients and carers may enact alternative ways of being (such as becoming friends) when there are extant power/knowledge relations. Therefore, there may also be a more positive task to be undertaken; redressing the power/knowledge relationship of the patient-carer-district nurse triad rather than merely removing that which subjugates them.

9.4 Power/knowledge

Foucauldian theorists (such as Butler), whilst differing on several aspects of knowledge, all agree that knowledge is tied to power, often terming it as Foucault did power/knowledge. This is to say that for those who have knowledge gain power by exercising this knowledge, power is then exercised to legitimise what knowledge counts as knowledge within a given field (Foucault 1977; Foucault and Gordon 1980; Foucault 2002). This dialectic process results in power/knowledge increasing one another to the point where they become indistinguishable and (re)form subjectivities (Butler 1997b; McNay 1999). Therefore, the changing of power/knowledge structures within a post-structuralist framework is not a straightforward matter; it becomes
necessary not only to understand knowledge, but the ways in which this knowledge exercises power and maintains legitimacy over other knowledge.

Chapter 7 demonstrated that patients' and carers' knowledge of district nursing services was generally derived from two sources. Mass media representation which had no direct connection with their district nursing services, was often dated, and offered little in the way of reforming patients' current discursive positions; and the performances of their district nurses, almost always limited to care that patients were currently receiving. Therefore, whilst patients and carers had ‘knowledge’ about district nursing, they lacked anything which could be considered detailed contemporary knowledge about their district nursing service which went beyond necessary first-hand experience or media representations. This prevented patients and carers accessing care such as equipment provision or psychosocial support, and planning future district nursing care such as end of life care. Therefore, if the (re)formations of district nurses observed in the empirical data such as ‘friendship’ are to be fruitful, it is necessary to problematise how they can produce resistance to a power/knowledge imbalance in the patient/carer nurse relationship.

9.4.1 Resistance and its problems

Power/knowledge and ways to resist have been examined from a variety of theoretical perspectives. Some authors espouse a radical approach to resistance where anything less than a complete re-writing/re-claiming of one’s subjectivity would perpetuate subjugation (Contu 2008; Dick 2008). However, other authors understand resistance as a process more properly termed ‘struggle’ where small subversive acts have the potential to lead to wider systematic change (Deetz 2008). How then may these different theorisations of resistance work for patients and carers within a palliative and supportive district nursing care context?
9.4.2 Who may and who should resist?

Within the literature on nursing care there has been discussion and critique around how nurses are subjugated by a biomedical discourse (May 1992; Peter et al. 2004). May (1992) considers how this influences what patients are/become by always being *subjects* of biomedical discourses but there is no attempt to consider how patients (and/or carers) may resist this subjugation. Peter et al (2004) argues resisting power is an ethical requirement of nursing but again only provide a brief discussion on how moral dilemmas may be handled to preserve patient autonomy. Instead, nurses are understood as ethically isolated individuals free from any connections with patients:

“The necessity of nurses to take collective action is also central… rather than focussing on single incidents that often reflect chronic problems, they should work on larger issues… lessening medical domination in clinical decision making… without these changes, nurses can come to accept the presence of moral problems and become less sensitive to them… [becoming] silent about their [nurses] moral distress… institutional management support for nurses moral actions is also highly important because it reinforces their confidence… [to] influence the multidisciplinary team” (Peter et al. 2004: 414)

This quote is typical of the focus placed on the nurses to resist *power/knowledge*. Within a nurse-patient-carer relationship it is the nurse who operates *power/knowledge* on patients through biomedical discourses which hold more legitimacy than other forms of *power/knowledge* (Foucault 1973; Foucault and Gordon 1980; Cheek and Rudge 1994; Cheek and Porter 1997). Nurses may benefit from this setup of *power/knowledge* relations through creating docile patients and decreasing workloads, yet within the literature no thought is given to how patients and carers, who are the focus of *power/knowledge* (indeed, give the very identity to nurses and other healthcare staff), can resist. Therefore, when considering resistance to *power/knowledge* whilst it is useful to consider how nurses (and other
healthcare professionals) can help reduce the power/knowledge imbalance, patients and carers must also be considered. Within palliative and supportive district nursing care the empirical data suggests that patients and carers face particular challenges: a deep reliance on nurses to maintain their health and comfort precluding more radical forms of resistance, a lack of and/or inability to network with other patients and carers, difficulty in accessing knowledge about district nursing from anything but district nurses. How then might these difficulties be overcome?

9.4.3 Knowledge provision as resistance

Appelin et al (2005) raised the possibility of providing more personalised information about community services. Similarly Hebert et al (Hebert et al. 2008) suggest providing prompt sheets for carers. This thesis has reiterated this idea in the interviews with the data demonstrating that knowledge beyond current physical care was not given by district nurses. Therefore, if subjective positions are to be expanded and resisted any knowledge that is given must aim to divulge the care which district nurses can perform even if patients and carers do not currently and/or overtly present with those needs. Such presentation of even that which is not needed (such as providing a prompt sheet) may help form new realities and expand the subjectivity of being a patient or carer and allow needs that are not currently considered viable by patients to become viable and hence expressible. Inevitably limits are still drawn but limits are a necessary requirement of subjectivity. What is important is that the knowledge that patients and carers develop about district nursing services is allowed to exceed beyond the extant discourses and performances of their current district nursing. However, theory warns that changing power/knowledge structures is not as simple as just providing knowledge, nor are its effects predictable (Jackson and Mazzei 2012). Whilst information leaflets on district nursing may be useful, the empirical data suggests, particularly for carers, that they may not redistribute power/knowledge relationships. This is because of the dialectic way in which power/knowledge
works, it is as much about what knowledge is legitimate knowledge and who legitimises knowledge as it is about what knowledge actually circulates (Foucault and Gordon 1980; Foucault 2002). Therefore, whilst increasing the circulation of knowledge is important (such as with an information leaflet or a prompt sheet), what must also be challenged is who has a claim to producing knowledge about district nursing and who is a valid subject of district nursing. To resolve this conflict, circulation of power/knowledge about district nurses must somehow be (at least partially) dislocated from the performance of district nursing; and any production of and distribution of knowledge about district nursing services must be carried out by patients and carers or a third party.

There are limited examples of this occurring with the Queens Nursing Institute (QNI) producing leaflets about home nursing care for patients (QNI 2011) but these fail to describe and/or expand the district nursing role beyond a biomedical/physical care discourse. Whilst independent from individual district nursing teams, the QNI is not independent from district nursing. Therefore, further research could be beneficial in building on this thesis in a patient and carer led way incorporating themes into information leaflets on palliative and supportive district nursing care such as: psychological support, befriending, equipment provision, and IV services.

9.4.4 Radical resistance

In addition to providing knowledge, other authors suggest radical forms of resisting power/knowledge. Radical resistance as suggested by Contu (2008) requires completely restructuring one’s subjectivity discarding all that one has been interpellated as and reforming one’s subjectivity with alternative discourses. This seems particularly risky for patients and carers with palliative care needs. If patients are patients of district nurses by virtue of having physical/practical care needs, and the patient narrative is disavowed and rewritten as something new then ‘patients’ risk having no recourse to aide for their physical needs which remain. This is a costly situation where needs and associated distress may continue, but any viable subjectivity of patienthood is
lacking to legitimately access services. Whilst radical resistance may work in other areas of society such as political resistance freeing oneself from oppressive states; the empirical data in this project suggests that for patients and carers district nurses are key in maintaining their home and identities. Therefore, radical actions seem unlikely to be beneficial or even possible. Only one case, P4 managed to resist and reject the involvement of district nurses but this was only possible by having physically able carers (husband and children) around her.

Deferring judgement about whether this is ‘good’ or ‘bad’ allows discussions for how power/knowledge comes to (re)form subjects and what the limitations of this (re)formation may be. In the case of P4, she had not actually made herself fully unviable and acknowledged that there may be times when district nurses were absolutely necessary; so whilst the power/knowledge grip of district nursing had been significantly loosened, it had not been fully rejected. Therefore, as theoretically distasteful some authors find smaller less radical forms of resistance, claiming that it achieves little to nothing (Contu 2008), when examining theories of resistance within the context of the empirical data, the ways in which patients and carers are maintained at home by their district nurses suggests less radical forms of resistance are necessary. These allow patients to maintain viable subjective positions that even to some small extent (as in the case of P4) maintain support networks, representing the only satisfactory way of theorising resistance for the majority of this group of patients and carers.

9.4.5 Networking and collective action as resistance

Other authors have examined resistance from the point of view of individuals being able to network and create connections to resist the subjugating effects of power/knowledge (Fleming 2008). However, the empirical data suggests that collective action by patients and carers receiving district nursing care is problematic because the majority of patients who received district nursing care for palliative and supportive care needs received it within their own home.
Whilst some patients were in contact with hospice daycare services and regularly came into contact with other patients and carers who received district nursing care, only two of these patients (P12 and P26) discussed their district nursing care with other patients. However, for P12 this conversation was prompted by the participating in the research project. Therefore, only one participant had previously discussed their district nursing care with any other patients or carers. This suggests that there is little opportunity or desire for collective action by patients and carers receiving district nursing care. However, even if patients and carers were to discuss district nursing care more often at locations such as hospice daycare centres or hospital outpatient clinics, it is unlikely that more than one or two patients would have the same group of district nurses. Taking collective action is therefore weakened when action would be dispersed across a wide range of services within multiple organisations.

A further barrier to collective actions for patients and carers are the ways in which collective actions would act. In this study, the only people who patients and carers met with who could influence their district nursing care were district nurses. Therefore, if an individual patient or carer wished to resist the discourses and structures of their care, it was their district nurses (i.e. those who are being resisted against) who were left with a responsibility to change the way they acted to those patients and carers. Whilst district nurses sometimes went beyond the biomedical discourses that initiated the patient-nurse relationship becoming friends, this reformation of district nurses whilst being moral (and hence contributing to quality of care) did not result in the distribution of knowledge about the district nursing services. To personify this argument, individual district nurses may become friends with patients and carers, creating feelings of confidence about future care them, but power/knowledge of district nursing was not reformed.

Theory suggests that those who hold power often refuse to acknowledge it or relinquish it (Foucault and Gordon 1980) and the empirical data suggests that this remains true for district nursing. This suggests that whilst reforming subjectivities along lines of friendship, counselling, and becoming younger are moral; when considering how these discourses influence prevailing
Frameworks their ability to produce further moral actions by disrupting is minimal. Therefore, ‘moral’ discourses remain moral but are tied to deeper underlying regimes that fail to be challenged by the lack of produced about district nursing for patients as evident in the empirical data presented in chapter 7.

Whilst physical isolation remained a reality for many patients and carers in this study this need not restrict patients and carers ability to act collectively. In a world that is becoming increasingly connected via the internet resistance is now being organised and even conducted through the internet (Zhang et al. 2010; Shirky 2011). Even within healthcare, patients and carers are able to, in a limited way, collectively influence each other’s choices through sites such as NHS choices (NHS Choices 2012). However, such sites do not allow for a social form of networking. Ratings are left, comments are made, but debate and socialising is prevented from occurring. In this way consumerism is allowed to function within the discursive framework as defined by NHS choices with a lack of debating and networking. Whilst this would appear better than no networking at all, NHS choices does not cover district nursing services meaning that for patients and carers of district nurses, even the basic commentary allowed for hospital and GP services is disallowed. Empirical evidence for suggesting such virtual forms of resistance are however limited in this study, and remain at the theoretical level. Therefore, further research into how virtual forms of networking may or may not work within this population would be needed before any firmer suggestions can be made.

In summary it was argued in the previous section on busyness that (re)forming district nurses with discourses such as friendship and kinship are moral. However, the morality of these actions is restricted because they do not result in any redistribution of between patients, carers and nurses. There are a wide variety of theorists that suggest differing ways in which can be resisted. Within this population the empirical data clearly seems to favour forms of resistance which allow the maintenance of current (patient and carer) and the continued production of acts which maintain these (various biomedical tasks). Therefore,
resistance may more properly be considered in terms of a ‘struggle’ which can
be facilitated through non-radical forms of resistance such as: increasing
patients’ and carers’ ability to network; and the distribution of knowledge about
district nursing services dislocated from district nurses themselves. The next
section addresses how the geography of district nursing care is strongly
implicated in how power/knowledge functions to produce moral actions.

9.5 The home

The analysis of empirical data with post-structuralist theory has revealed that:
district nurses reform the home as a viable space for care; they themselves
become viable by being a/the key source of that care; morality lies in allowing
patients and carers to reform their subjectivities; the home is (re)formed by
district nursing care; and district nursing care is (re)formed by the home.
Therefore, the home is not a natural pre-existing entity worthy of ontological
privilege but instead a discourse that is performatively enacted, continually
forming and reforming the home and the subjects who perform the home. This
challenges authors such as Liaschenko (1994, 1996, 2000, 2002) and Peter
(2002) who see the home as having a distinct meaning and forms the main
locus of power for patients. If as Liaschenko (1994, 1996, 2000) suggests,
nurses have an immediate and intrinsic affect on the home which is outside of
the patient’s, carer’s, and nurse’s control; then care can be considered
immoral because instantly the home becomes something which patients and
carers are precluded from reforming in any novel ways. However, this is not
what is occurring in the data from this research project. Patients and carers
suggested that district nurses had no affect on the home, or that this affect
could be sequestered away. However, the concept of ‘no affect’ within a post-
structuralist reading is not possible, all things are considered connecting and
affecting within post-structuralism; if there is no affect then there is no
existence; and clearly district nursing exists. Instead, within a post-structuralist
reading this lack of affect can be understood as power/knowledge hiding its
subjugating affects becoming a formative part of the home.
Within her discussion on (dis)ability Butler challenges the social model of disability suggest that it is not society that disables people but in fact society that enables everyone (Butler 2010). However, the power/knowledge structures that affect and enable people are only revealed as knowable when they begin to break down and fail to affect one’s ability to achieve normative standards; ability, and structures that produce ability are therefore hidden. The home may be considered in a similar way, constantly being maintained and performed through a variety of discourses. It is only when these discourses fail to maintain the home that the affects of the maintaining discourses become apparent. Therefore, if district nurses become maintaining factors of the home, their maintaining will not be noticeable to those who are maintained by them, and that which maintains one becomes inaccessible by forming the very conditions of one’s subjectivity.

Therefore, the home is maintained by district nurses and the possibility of rejecting district nurses would reject the home as a viable space for living, and as observed in chapter 8 the home becomes vital. Even P4 who rejected district nurses suggested that there was still some space for accepting district nurses into the home if “absolutely necessary”. In this way, the home becomes inseparable to the viability of the patients and carers subjectivities and the affect that district nurses have is hidden by becoming a necessity for existence within the home; the home that gives vital identity and existence. Home, nurse, patient and carer become inseparable.

In some of her most recent work Butler explores how loss of another subject produces a loss of the self:

“When we lose some of those ties by which we are constituted, we do not know who we are or what to do. On one level I think I have lost “you” only to discover that “I” have gone missing as well. At another level, perhaps what I have lost “in” you, that for which I have no ready vocabulary, is a relationality that is composed neither exclusively of myself, nor you, but is to be conceived as the tie by which those terms are differentiated and related” (Butler 2004: 22)
Whilst Butler’s language is almost always relating discourse to *subjects*, there is space within her argument to rethink the ways in which *subjects* are maintained in relation to the material as well as other *subjects*. This is not to assume that the material has some innate quality that gives it meaning. Nor is it to ignore the problems of how the material comes into being. Instead, one could argue that whilst *subjects* give the material its meaning, this meaning is not first given by the subject it gives meaning to. To do so would assume that *subjects* can give meaning before they are *subjects*. Instead, *subjects* must first logically become an acting subject within a material world before they can imbue meaning into the material. Therefore, Others must imbue meaning about the material into the psyche of the subject. In this way meaning within the material remains even if the Other who imbued the meaning does not. Therefore, the actions of the Other can act through the material by dictating the framework by which the material may be thought about by *subjects*. Understanding the material as a production of the Other opens up space to rethink the material as an expression of the Other (re)forming *subjects* through the material which is invested with meaning creating ties, creating relations, which give a subjective position to reside within.

“The home is a material and an affective space, shaped by everyday practices lived experiences, social relations, memories and emotions.” (Blunt 2005: 506)

The home, if understood as having ties to *subjects* can be thought of in the same way as a subject. This has two key implications for the interpretation of the data produced in this project. Firstly, if one were to act immorally towards the home, and the home affects *subjects*, then moral actions must not only include actions towards *subjects*, but also actions towards the material, the home. Secondly, if this were correct, and the home can be considered a subject in terms of morality then nurses actions have the potential to reside within the home even when they are not present. The ways in which care is set up demonstrate this, such as lounges becoming bedrooms. This conclusion alters the arguments on which home care is provided moving it away from economic arguments to moral arguments; and the morality lies in how patients and carers may (re)form the home. In addition it challenges the ideas put
forward by nursing theorists that ‘the home’ is merely psychically symbolic of high quality end of life care and can therefore be performed anywhere (Gott et al. 2004). Whilst it may be true to some extent that spaces can become ‘home like’ (hospices for instance), because these arguments consider the home to be a feeling (a psychic place rather than a physical space), they refuses to acknowledge and account for the materiality and vitality of the home and how it comes to reform subjectivities and actions; something demonstrated in this thesis to be key to how district nursing care is (re)formed. What then might this understanding of the home suggest for the production or preclusion of moral care?

If resistance has been argued to be a requirement to producing moral care, within palliative and supportive home care subjects are restricted in their resistance by a desire to maintain their home. Therefore, if subjects are to remain viable then resistance must not resist to the point of making the home an unviable place for care, something all subjects, even P4, abided by. To do so would remove a key component of patients’ and carers' identities which has been identified as being vital to maintaining one’s subjectivity. Therefore, resistance to the power/knowledge of district nursing is precluded by the way in which the home is maintained by district nursing. This challenges some authors who have theorised home care nursing as intrinsically producing better quality care than hospital nursing because of the lack of ‘distance’ that can be produced in the home (Gilmour 2005; Malone 2003); patients and carers in fact have less freedom to (re)form their care at home and therefore the production of quality care is curtailed.

What then can be said about resistance in material space where people (patients and carers) lack power/knowledge and risk their subjectivities in its reformation? How can theory help reform this bleak outlook of disempowered vulnerable docile subjects blinded to the effects of power/knowledge who may only be able to produce a superficial resistance which fails to truly redraw the lines of their subjectivity by continuing to perpetuate the power/knowledge of district nursing?
In his book on the sexual subculture of gay men and HIV Dean (2009) challenges the reader to understand how the laws governing material spaces are key to allowing moral actions to occur. Dean develops a compelling argument for unprotected sex amongst gay men (HIV positive and negative) as representative of an ethical openness to Otherness. Importantly Dean recognises that these ethical acts can be precluded or facilitated by the laws (law is not used here in a legal sense, but could be understood as ‘rules’ or ‘social norms’) that govern material spaces. For example, state law revoking licenses for bars which allow such actions to take place within them prevents what Dean considers moral actions from occurring. This understanding of the morality of being open to and promoting Otherness (a similar argument to that put forward in chapter 2) being restrained by laws which govern material spaces helps us understand how resistance may function when directed towards the laws governing material spaces (in this case the home) rather than at the individuals who act to (re)form the meaning of the material (patients, carers and nurses).

All the actions described so far within this thesis as ‘moral’ do not re-write the laws that govern what district nurses may do within a home. Whilst individual relationships have been demonstrated to be morally re-inscribed, there has been no evidence to suggest that it affects the laws that govern district nursing. Therefore, any gains in producing moral district nursing remain at an individual rather than a collective level where resistance is so often theorised to function. Whilst it is a reluctant conclusion, Dean’s understanding that moral actions are framed within laws which exceed the subject’s influence suggest that resistance which offers more than a superficial restructuring of subjectivities remains beyond the everyday acts that occur within the patient-carer-nurse triad. Instead, if patients and carers wish to produce resistance to power/knowledge there needs to be an engagement with the laws that structure the governing of the home. Whilst there were some forms of resistance observed in the data such as sequestering the things used by district nurses into boxes and becoming friends; these were few and far between and offered no way of redrawing the laws which governed district nursing. Therefore, the final section of this chapter theorises how the law (in
this case public policy) can produce or preclude moral actions within the home and how patients and carers with palliative care needs may have a meaningful engagement with these laws to (re)structure the power/knowledge of district nursing care.

9.6 Policy: producing morality out of materiality

It has been argued in this thesis that neoliberal reforms to healthcare cannot result in increasing quality care. Whilst an argument could be made about how to radically change the political organisation of care, this would not be congruent with the philosophical underpinnings of this thesis that suggest performatively reforming discourses rather than radical rewriting is the way to remain viable. Therefore, reforming neoliberal ideologies may be the only way to produce more moral care and reduce the ways in which patients and carers become subjugated to power/knowledge within the home. To do otherwise may theoretically be interesting, but may be of no practical use because it would result in a politically unviable reformation of healthcare policy.

Within current neoliberal forms of healthcare there is scope for patient and carer involvement, but there is no obligation (Department of Health 2010a; Great Britain 2012), and the ways in which involvement could be framed are unclear. Therefore, the rhetoric around patient and carer involvement in healthcare whilst commendable fails to account for and address the multitude of ways in which patient and carer involvement in healthcare is reduced and curtailed.

Individual resistance to these restraints should be encouraged and facilitated by removing obstacles to it, such as measuring quality of care. However, if care is to be ‘patient led’, patients (and carers) need to be more directly involved in the design and commissioning of care, rewriting the rules about what is and isn’t allowable care within the home by district nurses.

Whilst involving patients and carers on a practical level with palliative care needs in designing and commissioning services is difficult, the problems are
unlikely to be insurmountable as there are research studies which involve patients and carers with high rates of morbidity for prolonged periods of time (Charmaz 1991; Agar et al. 2008; Bakitas et al. 2009). Therefore, there is no reason to think participants couldn’t be found and engaged with if the desire were there. The more insidious problem would be enabling patients and carers to engage outside of the dominant *hegemonies* of district nursing and allowing resistance to these discourses to flourish. This is a harder task than it may appear at first because patients and carers must first be identified. As Butler suggests all identifications are essentially forms of subjugation, therefore, those with valid identities as patients and carers with palliative and supportive care needs are already subjugated to the discourses that one may hope to resist instantly limiting the possibilities of resistance.

How then might patients and carers be allowed to resist (more) outside of the influence of these discourses? The creation of forums which are not predicated on biomedical discourses, but instead, are self selecting may be the solution to such difficulties. Taking into consideration the geographical and physical limitation of potential participants, virtual forms of networking may be the most effective way of allowing patients and carers to network outside of a biomedical interpellation. Future research could pilot and develop electronic systems for individuals to interact with one another, exchanging information and discussing care; individuals in this way may be able to challenge district nursing practice safely away from the discourses that make them viable *subjects* of district nursing. Such forums could then form a fertile ground for patients and carers representatives to engage with other individuals to rewrite the rules on district nursing.

However, as highlighted earlier in the thesis, all the terms used such as patient, carer, palliative, and supportive are problematic. There are no clear dividing lines. Therefore, it may also be acceptable to have non-patients contributing to the process of reforming district nursing care, and in some ways, because non-patients are not subjugated by the discourses that patients are, may produce freer and more challenging ideas than patients alone would.
These forms of enhancing networking and bringing patients, carers and even non-patients into the design and purchasing process could then be combined to provide the opportunity for ideas to grow at least in part outside of the current hegemonies surrounding district nursing palliative care whilst also allowing a route into rewriting the laws that govern what district nursing is within the home. However, it should be noted involvement is just that, involvement. What is not being aimed for here is to replace biomedical hegemonies with patient and carer dictated hegemonies. To do this would be committing a parallel form of subjugation. As previously stated, biomedical discourses are not in themselves immoral, what is immoral is the ways in which they produce and sustain power/knowledge precluding the reformation of subjectivities.

The literature review at the beginning of this thesis suggests some of the topics that patients and carers may choose to articulate as being worthy of time and money when rewriting the rules around district nursing services such as relationship, continuity, maintenance of the home environment, access, and communication. However, up until now there has been little attention paid to how these values can become integrated into the services provided by district nurses. The approach that this thesis has theorised takes the rhetoric of a ‘patient led’ NHS which is derived from a neoliberal stance of consumerism and marketisation and examines what structures prevent the rhetoric becoming reality. It reduces the barriers to integrating patient and carers such as the hegemonies of biomedical discourses and the production of docile patients and carers. Addressing these problems then provides the means for the involvement of patients, carers and non-patients that stands some opportunity of resisting the current hegemonies of care at an institutional level by rewriting district nursing care at both in individual and institutional level.

In summary this way of conceptualising quality of care conflicts with several of the key ideas in the field of quality of care literature, and post-structuralist theory. Namely: measurement is not a way to produce quality; allow friendship and other non-biomedical discourses to form district nursing care is a sign of quality but it rejects the idea that nurses can ‘just be’ with patients; it draws attention to the need for patients and carers, not just nurses and healthcare
professionals, to have ways of resisting power/knowledge; moral action relates to the material as well as the discursive. The final section explores the implications for practice of these conclusions.

9.7 Implications of the research

Whilst many of the ideas in this thesis develop theoretical ideas and critique policy at an abstract level, there are some implications for practice that can be discussed from this thesis.

9.7.1 Measurement: what may remain?

It has been argued that nursing documentation can be given a dual purpose of being audited to measure quality (Donabedian 1969). Whilst in this thesis it has been argued for the removal of measurements to achieve quality of care, this is not an argument for the removal of all nursing documentation. Some documentation would undoubtedly need to remain if continuity and safety are to be maintained. For example, it will remain necessary to provide some documents to communicate the facets of care which would otherwise become unsafe and detrimental to patient care such as drug administration. However, it may be possible to identify documentation which is being primarily or exclusively used to measure and audit care rather than providing continuity and safety. Such documentation could be removed. Further research into district nursing documentation could explore this argument and the implications for practice.

9.7.2 Early support visits

The idea that district nurses provide early support visits and that they are viable has been challenged in this thesis. Only one patient received an early support visit (P4) and this was a particularly unviable act; all other participants
did not receive these visits. If early support visits are to be viable in the way that district nurses suggest they are i.e. achieving psychosocial support (Griffiths 1997; Griffiths et al. 2007). Then district nurses need to ensure that they are performing some viable discourses. Therefore, district nurses need to ensure that patients and carers consider their presence viable in the home when physical care tasks are not being conducted; particularly if an early support visit is the first visit from a district nurse. The data in this study from the final few interviews tentatively suggests that this could be achieved in two ways: written or verbal information delivered prior to a visit; or ensuring that the referring healthcare professional discusses with the patient why district nurses are being asked to visit. Further research on how to disseminate knowledge about district nursing early support visits would be beneficial. Either way, it is important the discourses that patients and carers use to form the idea of the district nurse prior to them entering the home encapsulate non-physical care if early support visits are to be viable and successful.

9.7.3 Pre-emptive information about district nursing services

Several patients raised the difficulties and problems with regards to a lack of knowledge about district nursing services, particularly when going in for planned major medical or surgical interventions which were highly likely to necessitate district nursing involvement afterwards. Again, data on exactly how to resolve this problem is tentative. There was limited evidence in the data for pre-admission referral to, and/or provision of information about district nursing services to help reduce the anxieties associated with uncertainty around transfer from secondary care to primary care. However, further research into how and what information is provided is required would be beneficial.

9.7.4 The home and the material

The value of home care in non-economic terms has been highlighted. Whilst there are sound arguments around the economic savings that one may make
through holding district nursing clinics as opposed to visiting individual homes, the change in environment reshapes district nursing care. This is something which is claimed within the district nursing literature (McGarry 2003; QNI 2011), but fails to go beyond rhetoric. This thesis has produced limited empirical evidence for this argument but its interpretation is heavily indebted to post-structuralist theory. Therefore, further research is needed to expand and deepen this particular theme, as it appears that the home may facilitate other care occurring other than just the biomedical task which initiated referral. Ethnographic methods may be particularly suited to these research questions.

Developing an understanding of the home and the role that it plays in (re)forming district nursing care, and the way that district nursing care (re)forms the home has been key to critiquing Butler’s performative theories. Whilst Butler unites the internal psychic life as described by the psychoanalytical theorists such as Freud and Lacan (Craib 2001), and the power/knowledge structures that permeate society as described by Foucault (1977; 1980). She fails to theorise how subjects affect and are affected by the material. This thesis tentatively suggests a way which remains congruent with post-structuralist theory by suggesting that the Other imbues meaning into the material by the ways that they act in relation to it. In this way, the material can be considered a production of the Other. Further research, both philosophical and empirical would help develop this understanding.

9.7.5 What is district nursing – the patient and carer perspective

It has become clear throughout this thesis that patients and carers do not understand the district nurse as a ‘holistic’ carer. They view them as predominately concerned with physical care tasks and this is only altered when district nurses act differently. The actions of district nurses, whilst sometimes timely, were not always so, and left patients with unmet needs, who were in regular contact with a healthcare professional, but remained ignorant of what district nurses may do for these needs.
The empirical data supports the findings of some authors who suggest that district nursing visits should continue after physical care is no longer necessary (Perreault et al. 2004). However, what care should occur within these interactions are not defined in this thesis; instead such decisions should be negotiated between patient, carer and district nurse.

9.7.6 Interactions with the patient

There is a need for district nurses to begin to, and allow interaction with, patients in ways that go beyond physical care discourses. The power/knowledge for this remains largely with district nurses and leaves a moral responsibility on district nurses to open up subjective possibilities for patients and carers to rewrite what a district nurse is. Whilst written information can go some way to beginning to open up these, as Appelin et al (2005) suggest, district nurses need to provide individualised information. Managerially this means allowing time and resources to be used in such an open-ended interaction.

9.7.7 Interactions with people other than the patient

More often than not carers were present in the home at the same time as the district nurse. However, at times it was reported that there was a lack of interaction between the carer and the district nurse. It was demonstrated in the empirical data that the district nurse merely briefly addressing the carer was appreciated and allowed dialogue to open up. In addition, whilst not specifically addressed with carers in this research, the above conclusion questions the extent to which carers are themselves receiving any form of assessment for their own needs from district nurse as legislated for in the carers act (Department of Health 1995).

However, this thesis resists adding more measurements to define what quality of care is (such as adding a measure to assess whether carers have been spoken to and assessed). Instead this thesis argues for the underlying
philosophy of district nursing to be altered to one which values opening up subjective possibilities. This allows this to be done in whatever way is most appropriate. For example carers may not wish to befriend the district nurse but instead access healthcare advice and services from the district nurse. So long as the desire to measure these interactions is resisted and rejected, then subjective possibilities will continue to be open and multiplied to carers. Again, management allowing time and resources to be justifiably used for such endeavours would help structurally support moral care occurring.

9.8 Conclusion

In conclusion, this thesis has reconceptualised what quality of care is and can be moving the discussion away from merely a unilateral consideration of the viewpoints of patients, carers, professionals, or funders. Instead quality of care has been reconceptualised as a dialectic process, which does not truly have its locus in one particular individual/subjectivity; it is a moral endeavour in relation to how discourses operate to produce or preclude a discursive (re)formation. When examining quality of care in this way in relation to the empirical data gathered in this project and wider literature there are several key implications, namely: that quality cannot be measured, and in attempting (and inevitably failing) to do so quality of care is precluded from developing; power/knowledge structures prevent patients and carers from accessing and critiquing care; and, the affect that district nursing has on the home is not limited to the discursive, instead moral actions also need to be considered towards the material.

The key implications for practice are: a need for greater information about district nursing services for those with palliative and supportive care needs; commissioning for palliative and supportive care must involve patients and carers; non-physical and non-medical district nursing care is a moral necessity and must be explicitly within district nurses’ roles so patients and carers are able to overtly rather than covertly access it.
This thesis has also developed a post-methodological approach to data analysis by hybridising grounded theory coding strategies with discourse analysis techniques. Similar combinations have been constructed in the past (Scharff 2011) but have failed to demonstrate how linking texts together via coding structures enhances analytical possibilities.

Further research may consider: employing in different settings, or reforming with alternative philosophies the framework in chapter 2; developing post-structuralist ways of considering the material in nursing care; developing the methodological challenges of accounting for the material in post-structuralism; and explicating post-structural methods of analysis.


Darzi, A. 2009. *High Quality Care For All*. London: TSO.


MacLure, M., Holmes, R., Jones, L., and MacRae, C. 2007. Silence as resistance to analysis. Or, on not opening one's mouth properly. In Annual meeting of the american educational research association. Chicago.


QNI. 2011. *Nursing People at Home: the issues, the stories, the actions*. London: QNI.


Appendix A – Glossary

*Subjectivity* – In post-structuralist writings the concept which encapsulates the discursive position that is carved out in language that individuals will then go onto occupy but not possess.

*Subjects* – Individuals who occupy *subjectivities*

*Power/knowledge* – A Foucauldian term which posits that knowledge is linked to power by using knowledge to regulate the conduct of others. This power then regulates what is viable as knowledge. Power and knowledge then feed on each other becoming indistinguishable.

*Dialectic* – Used in its Hegelian formation in this thesis to denote the process and concept of *subjects* only gaining meaning by relating to the *Other*. For example, a slave is only a slave by having a master, and equally a master is only a master by having a slave. Therefore, the slave has power over the master by dialectically granting him his identity but there is no way of tracing in a linear fashion which came first.

*Hegemony* – Used in its Marxist sense to describe the cultural norms and rules imposed by the dominant ruling classes.

The *Other* – A psychoanalytical term to conceptualises the process through which a newborn baby comes to recognise itself as individual. Psychoanalytic theory posits that initially a newborn child has no sense of self, it gains this sense of self through recognising that there are Others which it is not. In this way, a psychic and social separation occurs which is reliant on the child recognising that there is *the Other* and indeed that the self is an Other to others.
Appendix B – Initial interview protocol

Version 1

**Interview Guide**
This guide will be developed iteratively as the research study proceeds and new data emerges

**Code:**
**Interview number:**

**Opening Questions**
What are patients’ experience of DN care?
What do they consider to be high quality care from district nurses?
Why? How? Who?
What sorts of things do DN do for patients and carers?
Talking?
Technical/medical?
Social support?
Co-ordination?

Which things make care better?
How do these things influence the quality of care?

**Relationship**
What sort of relationship do patients and carers have with their DN?
How does this develop?
Does this affect the quality of care received? How? Why?
Are their DN friendly?
Interview Protocol

**Time Keeping**
What are patient and carers views on DN time keeping? Promptness
Does this help/hinder care?
Does this differ out of hours?
Do you get a time slot? How broad? How much in advance do you know?
Unannounced visits - had any? If so opinion (good/bad?)

**Care at home**
What are patients and carers feelings about nurses coming into their home?
What are patients and carers feelings on equipment at home?
Does this effect quality of care? (Is it intrusive? Does it stop 'home' being home?)
Interview Protocol

**Continuity**
Do patients and carers see the same DN all the time? Same group?
How do they feel about this? How does it affect quality of care?
If different nurses, do they know them? How does this affect quality of care?

**Closing questions**
Anything else patients want to discuss?
Any questions for me?
Thank for participation
## Appendix C – Data extraction sheet

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### Design

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### Sample

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<td>Inclusion/exclusion criteria</td>
</tr>
<tr>
<td>Characteristics of sample</td>
</tr>
<tr>
<td>---------------------------</td>
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</tbody>
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**Statistics**

Which statistical tests were used?

Details:

**Summary**

Author conclusions

My conclusions

Endnote summary

**Implications for Quality**

Patients

Carers
Appendix D – Patient consent form

Patients’ and carers’ views on what is quality palliative and supportive care from district nurses

Initial:

1. I confirm that I have read and understand the information sheet dated .......... (version......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my healthcare care or legal rights being affected.

3. I give permission for interviews to be audio-recorded.

4. I give permission for my audio-diary to be transcribed

5. I give permission for anonymised quotes to be used in any publications.

6. I agree to take part in the above study.

7. I agree to my GP being informed of my participation in the study.

8. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS trust, where is relevant to my taking part in this research, I give permission for these individuals to have access to my records.

_________________________  ______________________  ______________________
Name of patient            Date                        Signature

_________________________  ______________________  ______________________
Name of person             Date                        Signature
taking consent

On completion: 1 copy for participant, 1 for researcher, 1 for the medical notes.
Appendix E – Carer consent form

Patients’ and carers’ views on what is quality palliative and supportive care from district nurses

1. I confirm that I have read and understand the information sheet dated …… (version……) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my healthcare care or legal rights being affected.

3. I give permission for interviews to be audio-recorded.

4. I give permission for my audio-diary to be transcribed

5. I give permission for anonymised quotes to be used in any publications.

6. I agree to take part in the above study.

7. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS trust, where is relevant to my taking part in this research, I give permission for these individuals to have access to my records.

Initial:

Name of carer                   Date                   Signature

Name of person taking consent  Date                   Signature

On completion: 1 copy for participant, 1 for researcher, 1 for the medical notes.
Appendix F – Reply slip

Reply slip

I ........................................................ am interested in taking part in your study.

Address: .................................................................
                    .................................................................
                    .................................................................

Town: .................................................................
Postcode: .................................................................
Email (if applicable): .................................................................
Telephone: .................................................................

Preferred contact (please tick):
Telephone □
Email □

Name of district nurse: .................................................................
District nursing team: .................................................................

Signed ................................................................. Date: .................................

Combining the strengths of UMIST and The Victoria University of Manchester
What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk. You may also contact your local PALS on 0161 xxx xxxx

What do I do next?

Please let me know if you would like to take part in the study by returning the reply slip.

Further Questions?

If you are interested in taking part but have further questions. Please contact me.

Maurice Nagington
PhD Student
The School of Nursing, Midwifery and Social Work
University of Manchester
University Place
Oxford Road
Manchester
M13 9LP mail: Maurice.nagington@postgrad.manchester.ac.uk
Tel: xxxxxxxx
What is the purpose of the study?
We don’t know much about what patients think is quality care from district nurses. We have investigated what healthcare professionals think. I would like to interview you to get the patients’ perspective.

Why have I been invited to take part?
You have been invited because your healthcare professional feels that you may offer an insight into the experience of being cared for by district nurses.

Do I have to take part?
No, it is up to you to decide whether or not to join the study. Your care will not be affected either way.

What is required of me if I do take part?
Subject to your consent I hope to conduct two interviews with you. I anticipate these will be about an hour long, however they may be longer or shorter. They will be done at your home or place of your choosing about one month apart. In-between the interviews I will ask you to keep a diary (audio tape or written) for one week about your thoughts and experiences of district nursing care. Any travel costs will be reimbursed.

What are the possible advantages and disadvantages to taking part?
Hopefully your participation will help improve care in the future. Some people may find the topics and discussions upsetting but other patients may find it helpful to talk to somebody. Either way I am an experienced nurse used to discussing sensitive issues with patients and carers. If you feel upset the interview will be paused and you can take a break or you can withdraw from the study.

Will my taking part in this study be kept confidential?
Yes, all information gathered in this study will be kept confidential unless there is a possibility of harm occurring to you or others. Interview transcripts will have identifiable information removed. All electronic information will be kept on an encrypted University laptop computer. If you wish you are entitled to receive a copy of the transcript to check it for accuracy.

Will you involve any of my healthcare team?
Yes, I will need to contact your district nurse to see how much care they give you. Your GP will also be informed that you are taking part.

Who is organising and funding this research?
This is being funded by the Dimbleby Cancer Care Research Fund and The University of Manchester. Karen Luker and Catherine Walshe are the educational supervisors.

Who has reviewed the study?
This study has been reviewed and approved by the University of Manchester Ethics committee and Greater Manchester East NHS Research Ethics Committee.

What will happen to the results of the research study?
Full research results will not be ready until two years after your interviews have take place. I will write up a short report for all participants. I will contact you when it is ready and send you a copy if you wish to read it. Anonymised data will be kept in the University of Manchester’s archive for up to 10 years. Anonymised quotations may be used in publications.
What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk. You may also contact your local PALS on 0161 xxx xxxx

What do I do next?

Please let me know if you would like to take part in the study by returning the reply slip.

Further Questions?

If you are interested in taking part but have further questions. Please contact me.

Maurice Naggington
PhD Student
The School of Nursing, Midwifery and Social Work
University of Manchester
University Place
Oxford Road
Manchester
M13 9LP
mail: Maurice.g.naggington@postgrad.manchester.ac.uk
Tel: xxxxxxxx

Carer Information Sheet

Patients’ and carers’ views on what is quality palliative and supportive care from district nurses

I would like to invite you to take part in a research study investigating the views of patients with severe or life limiting illnesses and their carers on what is quality care from district nurses. It is not intended to be counseling of psychological care. Before you decide whether to take part I would like you to understand why the research is being done and what it would involve for you.

If you are interested please continue to read this information sheet. There is a reply slip included in this pack. You may also contact me to discuss it further (details on last page). It should take you no longer than 10 minutes to understand what this study is about.
What is the purpose of the study?
We don’t know much about what carers think is quality care from district nurses. We have investigated what healthcare professionals think. I would like to interview you to get the patients’ perspective.

Why have I been invited to take part?
You have been invited because your healthcare professional feels that you may offer an insight into the experience of being cared for by district nurses.

Do I have to take part?
No, it is up to you to decide whether or not to join the study.

What is required of me if I do take part?
Subject to your consent I hope to conduct two interviews with you. I anticipate these will be about an hour long, however they may be longer or shorter. They will be done at your home or place of your choosing about one month apart. In-between the interviews I will ask you to keep a diary (audio tape or written) for one week about your thoughts and experiences of district nursing care. Any travel costs will be reimbursed.

What are the possible advantages and disadvantages to taking part?
Hopefully your participation will help improve care in the future. Some people may find the topics and discussions upsetting but other people may find it helpful to talk to somebody. Either way I am an experienced nurse used to discussing sensitive issues with patients and carers. If you feel upset the interview will be paused and you can take a break or you can withdraw from the study.

Will my taking part in this study be kept confidential?
Yes, all information gathered in this study will be kept confidential unless there is a possibility of harm occurring to yourself or others. Interview transcripts will have identifiable information removed. All electronic information will be kept on an encrypted University laptop computer. If you wish you are entitled to receive a copy of the transcript to check it for accuracy.

Who is organising and funding this research?
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Appendix I – Diary guide

Diary Instructions

Please spend a few minutes each day for one week recording your thoughts on what did or didn’t improve the quality of the care you and your friend/relative received. Ideally this should be done after a district nurse has visited/contacted you but if this is not possible please just record your general thoughts and feelings which may include:

- What the district nurses say
- What the district nurses do
- How they say things
- How they do things
- How they organise the care they give you
- Do you think they spend enough time with you?
- Any other things that you think effect the quality of the care you receive.
### Appendix J – Demographic details

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<td>P1</td>
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<td>Ca Lung</td>
<td>Engineer</td>
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<tr>
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Appendix K – Interview protocol second iteration

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**Interview Guide**
This guide will be developed iteratively as the research study proceeds and new data emerges

**Previous DN contact**
Have you had previous contact with DN? What? Who? For? How long ago? Compare to this current involvement...

---

**Opening Questions**
Previous Knowledge of DN

Had you heard of DN before now?
How?
What?
What did you think they did?
Why did you think this?

Relationship

What sort of relationships do patients and carers have with their DN?
How does this develop?
Does this effect the quality of care received? How? Why?
Are their DN friendly?
Interview Protocol

**Time Keeping**
What are patient and carers views on DN time keeping? Promptness
Does this help/hinder care? How/why?
Does this differ out of hours? How/why?
Do you get a time slot? How broad? How much in advance do you know?
Unannounced visits - had any? If so opinion (good/bad?)

**Care at home**
What are patients and carers feelings about nurses coming into their home?
What are patients and carers feelings on equipment at home?
Does this effect quality of care? (Is it intrusive? Does it stop 'home' being home?)
Interview Protocol

Continuity
Do patients and carers see the same DN all the time? Same group?
How do they feel about this? How does it affect quality of care?
If different nurses, do they know them? How does this affect quality of care?

Closing questions
Anything else patients want to discuss?
Any questions for me?

Thank for participation
Appendix L – Interview protocol third iteration

Interview Guide
This guide will be developed iteratively as the research study proceeds and new data emerges.

Previous DN contact
Have you had previous contact with DNs?
What/Who for?
How long ago?
Compare to this current involvement...

Opening Questions
What are patients experience of DN care?
What do they consider to be high quality care from district nurses?
Why? How? Who?
What sorts of things do DN do for patients and carers?
   Talking?
   Technical/medical?
   Social support?
   Co-ordination?

Which things make care better?
How do these things influence the quality of care?
Previous Knowledge of DN's
Had you heard of DN's before now?
How?
What?
What did you think they did?
Why did you think this?

Relationship
What sort of relationships do patients and carers have with their DN?
How does this develop?
Does this effect the quality of care received? How? Why?
Are their DN friendly?
Affect, sticky emotions?
Interview Protocol

Time Keeping
What are patient and carers views on DN time keeping? Promptness
Does this help/hinder care? How/why?
Does this differ out of hours? How/why?
Do you get a time slot? How broad? How much in advance do you know?
Unannounced visits - had any? If so opinion (good/bad?)

Care at home
What are patients and carers feelings about nurses coming into their home?
What are patients and carers feelings on equipment at home?
Does this effect quality of care? (Is it intrusive? Does it stop ‘home’ being home?)
Interview Protocol

Continuity
Do patients and carers see the same DN all the time? Same group?
How do they feel about this? How does it effect quality of care?
If different nurses, do they know them? How does this effect quality of care?

Regime of truth/ability to discuss with others
Do you ever discuss your DN care with other people/patients/professionals?
If so, what do you discuss?
Have you found out anything new that DNs could help with?
Interview Protocol

**Touch**
Do DN use touch?
How do they use touch?
What effects does it have?

**What do you do for your DN**
Do you do anything for your DN?
What?
Why do you think that?
**Information sheets**
Would you benefit from having an information sheet on DN services?
On community palliative care services?
What sort of information would you benefit from?

**Closing questions**
Anything else patients want to discuss?
Any questions for me?

Thank for participation
Appendix M – Transcription confidentiality agreement
Appendix N – Coding for interview with P16 and C16

P16: (Was it the diabetic nurse that got you going to the hospital?)
C16: To the hospital?
P16: It was to the hospital, wasn't it?
C16: Yeah, I went to the hospital. It was the diabetic nurse that organized that.
P16: Oh, the diabetic nurse. Did she call you?
C16: No.
P16: What did the diabetic nurse call you about?
C16: Not sure. I think it was to see the diabetic nurse in the hospital.
P16: Were you in the hospital because they asked you to come in? No, it wasn't because of your diabetes.
C16: No, it wasn't because of your diabetes.
P16: Was it to see the doctor or was it a check-up?
C16: No, it was a check-up.

Interviewer: (In the day centre, day care?)
P16: Oh, I thought you'd seen your doctor.
C16: No, they had a routine check-up.
P16: Oh, I thought that.

P16: I said to the diabetic nurse, I keep feeling a bit low, and she said well you should go to the doctor. I couldn't think of anything to do, the last one. I think I was discharged later, because it was so much. I'm not sure exactly what I think, though I'm feeling a bit better. So, was it one of the nurses from the hospital who asked you to come in?
C16: The diabetic nurse asked me to come in.

Interviewer: (So for the doctor?)
P16: You just mentioned that you were feeling a bit low and mentioned it was the diabetic nurse that called you?
C16: It was the diabetic nurse who called.
P16: Sister, anyway, she's a sister, and I just mentioned that to her, you know.
C16: It was the diabetic nurse who called.

Interviewer: And that's when it came that you were feeling a bit low.
P16: That's when she said, well, you know, I think we should probably talk about that, and what about going to the hospital, and I said well, I wouldn't mind, you see.
C16: I think we should probably talk about that, and what about going to the hospital, and I said, well, I wouldn't mind.

Interviewer: (Laughter) you.
P16: When you know, alright, I got involved with the outside of it, and I got involved with the outside of it...
C10: [Edgar]: You need a couple of times, didn't you? Then you were going and you said I'm going to bed from the week. I don't think I should be here now. I don't think I should be here now. I don't know what's going on here. That's where we're at, and then we're doing something at the home and things like that. I'm going to bed from the week. I don't think I should be here now. I don't know what's going on here. That's where we're at, and then we're doing something at the home and things like that.

P10: They did, yes.

C10: And that was it on you, and then there's been all the time till this evening. And then this time, he said...

P10: [Edgar]: It's been coming along enough, few had enough now.

C10: [Edgar]: And it's been coming along enough, few had enough now.

P10: [Edgar]: That was the first I started getting. I've lost a lot of people who've been through, and I'm going to bed with them and then next thing they're... well, you know they're all right and then they're gone.

Interviewer: Yeah, I suppose it is.

P10: [Edgar]: It's all gone to you, does it?

Interviewer: Langtime, yeah.

P10: [Edgar]: When you pass somebody else, like this morning I went and there was a bloke, there's usually into, he looked terrible this morning, he looked terrible.

Interviewer: So have the distinction themselves over spent much time in the home, that she looks at you and she sees you're feeling a bit low, but there's not much time there's no, there's no time left for talking with you and doing emotional support.

P10: No.

Interviewer: No. But they have picked up...

P10: ...only this morning, as I was a bit, you know, she said that you were the... you were the one that was being the one that was being the... the one that was being the one that was being the one that was...

Interviewer: ...and that you were there even they could have picked up on it, but they didn't.

P10: Not really no.

Interviewer: No, and this is a question: is people because one of the issue, you no home so their social life, and she's shaped that sometimes she's been away and doing, out of medicine question around diagnosis and things, and that's going on to you?

P10: No, not with distinct issues. I wasn't even calling doctor.

C10: No. No.

P10: Help's not always there anyway. Can't be in subject don't think.

Interviewer: Okay, when he had never come up with the distinction because, it's something you've wanted to discuss, is it?

P10: No, he never discussed it with them. Only what I'm going for.

C10: The dialect never comes to a job, do the other... And now to see them for, a certain thing. If you've any other people, you go to your doctor. That's how we do it, isn't it?

P10: Yeah.
## Appendix O – Summary of coding for all interviews

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Average number of codes: 178
Appendix P – Excerpt of interview with coding stripes: P6 ‘future care’

I Oh Claire is the OT.

P6 Here about two years I think.

C6 But the district nurses are always there if I need them which they will eventually be involved a lot with him.

P6 Oh aye, Oh it’s going to come.

I So what do you think the district nurses will do for you in the future then?

C6 He will end up being in bed more than anything so that’s where they’ll get involved probably washing him down, changing his pyjamas, because of all my problems, I mean I’ll do what I can. Making sure he’s got the right medication and do what they can. Sort him out sort of thing to save him going into hospital, they’ll get a doctor out if they need to, also they will be very helpful when the time comes.

P6 Everybody I’ve had in the last eight or nine years have been excellent, no complaints at all.

I Is that something the district nurses have discussed with you then, what they can do?

P6 Yes when they first started, when the palliative care first started they said they want to be here for me.

I Right okay.

P6 Not that I remember, my memory is as short as my breath.

I No that’s fine. So how often are the district nurses making contact at the moment then?
## Appendix Q – Overall coding structure

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Appendix R – Coding structure for busyness

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<tr>
<th>Busy discourse</th>
<th>Media representations of busyness</th>
<th>Discourse of busyness declared or interpellated onto DNs from media</th>
<th>Effects of busyness discourse</th>
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<tr>
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<td>Interview representations of busyness</td>
<td>Discourse of busyness declared or interpellated onto DNs from media</td>
<td>Disorganisation</td>
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<td>Actions read as symbolic of busyness</td>
<td>Lack of chatting</td>
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<td>Declining a drink</td>
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<td>Good care despite busyness</td>
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<td>Short visits</td>
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<td>Busyness and prioritisation</td>
<td>Busyness = not doing leg dressings</td>
<td>P25 blood being done for DR - i.e. more authority</td>
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<td>P25 blood needing done = priority over other pts</td>
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<td>P25 feels nurses prioritise caring for 'bedfast' patients over her</td>
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<td>P25 feels other patients are 'worse than her'</td>
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<td>P25 well and DNs 'busy' = no visit</td>
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<td>Double think busyness</td>
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N.B. many headings at the various levels had additional codes which were not organised into themes as they did not easily group together. For the sake of brevity these are omitted but an example of this is shown under the heading ‘busyness and prioritisation’ where codes remain such as ‘P25 blood being done = priority over other patients’.
Appendix S – Memo of busyness

17 out of 26 participants mentioned the word busy or busyness in relation to the DN (this doesn't even include various synonyms such as rushed or hurried)

This is ALMOST an extant discourse and ALMOST something that is performed. It appears to be both, one playing off the other where extant discourses of 'busyness' in the NHS (C14, C15, C21, P16) and this results in certain actions as being read as signs of busyness i.e. not chatting and short visits (P16), declining a drink (P5), and disorganisation (C14).

These discourses seem to circulate in the media, alot of the time I feel this is a discourse pushed by the media.

If anything DNs appear to manage to create a 'double think' (see effects of busyness memo) which benefits them where they are perceived as 'busy' yet act and speak as if they have plenty of time for the patients (see interview with P1).
Appendix T – Diagram of busyness

- Reasons for organisation of time
- DN timekeeping
- Effects of timekeeping
- Ways to improve timekeeping
- DN organisation of timekeeping

Busyness

Effects of busyness

= memo

= theme

= sub-theme
Appendix U – Memo of ‘Timekeeping and prioritisation’

Here we see that patients perceive that nurses poor timekeeping or lack of a time slot is because they prioritise their care. P7 clearly has ideas that district nurses deal with far more acute care such as "gushing blood". The holding of this truth about district nurses quite justifiably produces the idea that his care is a lower priority and that his care is "fitted in" with other peoples care. Here we begin to see that patients having a great paucity of knowledge on what DN s do not only impinges on their ability to access services (see other chapter) but also their ability to assess whether their care is quality care or not. This may link the the idea that district nurses are busy with other important care and prioritise.

This is quite interesting. P7 sees DN s as prioritising and gives the example of his line flushes vs someone gushing blood. In this scenario he gives the DN s leeway because gushing blood comes first, line flush second. Whilst this is has internal validity, it appears to an extent that the sees these major prioritisations as a day to day event that result in his care being shifted about on a regular basis; he therefore seems to lack a clear knowledge of what DN s are faced with on a day to day basis and conflates a reality for them (one presumably from discourses that they tell him and the media tell him) which supports their erratic timetable.
Appendix V – Memo of ‘Effects of busyness’

The idea that DNs, nurses, and the NHS in general are busy, is a discourse that strongly circulates in media (need to work this in). This discourse has several effects. Firstly it leads to a kind of self policing of the ways in which patients and carers access healthcare C6 "They work hard enough, they've got enough to do and if you can manage, you manage". This suggests that carers in particular do not ask for increasing help from DNs not just because they don't know the services exist (which they more often than not don't) but also because they perceive the DNs as too busy to do extra tasks anyway. For example, the idea that nurses are busy reduces the expectation of social visits

Interviewer: But would you expect district nurses to come, just to drop in, see how you are?
P16: No.
C16: No.
Interviewer: No? No?
P16: No, no.
C16: Do other people expect that?
Interviewer: Well some people do. I mean is it something you think you would need or?
P16: It would be very…
C16: Not at this point in time, no.
P16: No, but it would be nice to know that somebody cared, that they just called in, but I would, I don’t know, I wouldn’t expect it because…
C16: You see we always see them with this list of drugs, don’t we, that they’ve to get done in so much time… P16: It would be a confidence builder, yeah. But that’s all. You know, it would take too much time on, NHS time, so, I wouldn’t expect that to happen."

The idea that the nurses have a long list of drugs therefore can be read as DNs being busy with more important biomedical tasks, this makes the care that P16 does seem to desire unviable when DNing care seems to be dictated by a hierarchy of what is legitimate DNing care which is delimited by extant
discourses on nursing and DNing care in the media and is then reinforced by nurses not

Busyness also explains for C14 the poor link between hospital and community services because DNs are 'too busy' to come to hospital and meet the patient.

For P16 the idea that DNs are busy also explains why they don't chat much with him.

DNs being busy is also used as a reason for DNs using answermachines (C15 and C16) which many patients find frustrating (ref other interviews).

There are clear benefits for nurses appearing "busy" and "hurried". They seem to maintain this discourse through poor timekeeping and occasional comments to patients and carers. However, then breaking the expectation of hurried care then leads the them being valued and offering quality care to the individual patient. Despite the fact that patients often feel unable to ask nurses certain things or to do certain things. A lack of overtly performing being hurried by the district nurse, even though this discursively comes to form the district nurse, with individual patients then becomes a sign of quality.

This is an interesting was of putting things. The way she phrases "the fact that they are in hurry" where is the basis for understanding this? WHY does she think they are in a hurry? Is it a discourse of 'hurried' healthcare professionals? Possibly, because if they WE'RE PERFORMING a discourse of hurrying then she would not follow it up by the statement "even though they are not". Therefore, the DN benefits from being interpellated as a 'hurried subject' and then not performing this discourse.

The discourse of 'being hurried' appears to be something that isn't only applied to healthcare professionals but EVERYONE, "your own family". This lack of hurrying therefore signifies that they are their only focus: "the most important
thing". Therefore, the discourse of 'being hurried' which is used to construct the DN, when that performance ISN'T fulfilled is a sign of greater care taking place and a sign of quality. When an expectation is broken in a positive way.

Combining this with the other memos on busyness we can see that busyness both exonerates DNs from doing alot of non-viable non-biomedical whilst also serving as a way of DNs being 'super nurses' by acting as a barrier to the busyness of the NHS and not allowing this into the patients home.
## Appendix W – Coding structure for P3

| Surprised GP came to house | Specific bad experience | Respect | In a performance |
| Patient characteristics | Unannounced visit | Pt relationship with DN is ‘relaxed’ | Surprised re DN involvement |
| Bad nursing experiences | Cellulitis | How relationship formed | Exant discourses |
| Pt discourses on DN | DNs Failing to turn up | Official knowledge of DN difficult to obtain | |
| Previous experiences and ideas of DNs (extant discourses) | Continuity | Timekeeping | |
| Confidence | Relationship | DN power | |
| Pt relationship with DN is ‘relaxed’ | | DN visiting | |
| How relationship formed | In a performance | Genesis | |
| | Exant discourses | Cessation | |
| | | Continuation | |
| Pts home | Clutter | |

N.B. many headings at the various levels had additional codes which were not organised into themes as they did not easily group together. For the sake of brevity these are omitted.
Appendix X – Coding structure for P16

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<td>DN lack of knowledge</td>
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<td>P16 characteristics</td>
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<td>Genesis of DN involvement</td>
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<td>Transfer from home to clinic care</td>
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<td>Continuity</td>
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<td>DNs out of hours</td>
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N.B. many headings at the various levels had additional codes which were not organised into themes as they did not easily group together. For the sake of brevity these are omitted.
Interviewer: I'll pop that nearer you because it'll pick you up. I don't know if you want to start by just telling me a bit about yourself in general and I'll tell you a bit about me and how I've ended up...

P7: What do you want to know, my health or what? That's quite interesting really isn't it?

Interviewer: I am interested in your health but maybe a little bit about what you used to do workwise.

P7: Workwise, I started off as an apprentice engineer and I went into the drawing office most of my life and then I became an engineer's assistant and then I became a project engineer. That's basically my medical of working life. I retired at 59, I was retired on my health because my aorta burst.

Interviewer: Crikey, good grief.

P7: There it is. I was one of the very few people to survive it, one of the very first people to survive it. I finished work then and I've been retired ever since.

Interviewer: Do have any children as well?

P7: Yes, we have two boys and one girl. [Son's name] the eldest, he's 50 this year, funnily enough. [Second son's name] is the next one, he's 49 this year, and then there [Daughter's name] our daughter, don't know what age she is, actually. [Laughs] I can't think of what it is. Somewhere around about 45, something like that. Grandkids - our eldest son, we've got a granddaughter with him but we very rarely see her because he's been divorced and then remarried. [Second son], the middle one, he's also been divorced and remarried but they've no children. My daughter, [Daughter's name], she's got two children - a boy and a girl. [Grandson's name] being 18 and [Granddaughter's name], 15.

Interviewer: Do they all live locally then?

P7: Fairly. [Son's name], the eldest, he lives in [Local town]. [Second son's name], the next one, he lives in [Local town] and [Daughter's name] lives in [Local town], just up the hill.

Interviewer: So they're all within...

P7: They're all within 50 miles.

Interviewer: My background's in nursing. I worked at St Ann's Hospice just over in Little Hulton in Salford. I started this research project 18
months ago mainly, as I say, to look at what people find gives them good quality to their care from the district nurses. That's trying to think beyond the medical side of it as well, so thinking about them as people and all that sort of thing. There's been a lot of research done looking at what the district nurses themselves think gives good quality care and Macmillan nurses and the healthcare professionals. There's been quite a lot of work done with carers of, but very few people have spoken to the patients whilst they're getting care from district nurses.

So that's the main reason to do it, just to see how people like your perspective compares to the district nurses and whether there's things that you really value that the district nurses don't recognise as much, it's things like that really. You're the seventh pair of people, not everyone's got a wife to interview as well. You're case number seven so it's still quite early days in some ways. I don't know if you want to just tell me a bit about your history and how the district nurses ended up coming to visit you, really?

P7: Like I said, my aorta burst in 59 and obviously they came to see to me then. I had scar tissue, they know it from this down here. About three and a half years ago I went to the doctor bleeding from my backside so, of course, he sent me to [local hospital] and they found I'd got bowel cancer. So they removed the bowel cancer hoping they got rid of everything but, unfortunately, it had travelled to my liver and I've got seven tumours in my liver which they can't operate on. I've now got terminal cancer.

A couple of weeks ago I was in the kitchen with [C7] and I just flaked out on the deck, got taken into [Local hospital] again and the outcome of it quickly is that my heart had stopped beating for 13 seconds and so they had to put a pacemaker in. I've now got a pacemaker in, fitted a couple of weeks ago. That's basically my medical history. Apart from when I was two and a half years of age I fell in the fire and badly scalded myself - that's the scars on my neck there, and then one on my shoulder and one there and there.

Then again, the war was on and so they basically sent me home to die and said there was nothing they could do with me. They sent me home to die and again I survived for some strange reason. That was it.

Interviewer: Do you mind me asking how old you are now?

P7: Not at all - 73.

Interviewer: I suppose what I'd like to ask initially is - when you had the aorta
burst, had you ever had district nurses come before then to either yourself, your wife, your children or your parents or anything?

P7: Not that I ever remember, no. It's purely my illnesses that I've had medical nurses.

Interviewer: Did you have any idea of what a district nurse was for before they started coming to visit you, what you thought?

P7: No idea at all.

Interviewer: Had you heard of district nurses?

P7: I'd heard of them vaguely, just vaguely. They weren't something we even thought about.

Interviewer: So you knew there were the people who were district nurses?

P7: To help you with, if you had problems. We had no dealings with them or anything.

Interviewer: Would you have had any idea of what sort of problems they helped people with?

P7: At that stage I wouldn't know really, it was just a district nurse and that was it. It was a name.

Interviewer: It was a name and no other things attached?

P7: No connection because we had no connection to them.

Interviewer: I suppose it would be interesting for me to ask about - I know your main problem now is the bowel cancer and…

P7: Not the bowel cancer, I've passed it now…

Interviewer: Sorry, the liver cancer.

P7: …the liver cancer.

Interviewer: If maybe I could spend a little bit of time talking about the first time you met the district nurses for yourself after the aortic operation and talk more about the liver and what they're doing for you now - is that okay?

P7: Yeah, of course.
Interviewer: When they came in - sorry, go on.

P7: To be honest with you I can say very, very little about the time when the nurses came to see me about my aorta bursting because [C7] can tell you much more that I can about that, because I had a stroke at the same time as waiting for surgery - I had a stroke. The first two years basically is a blank. I just don't remember anything. I knew they came and did this to me, this that and the other, but I can't tell you much about them. [C7] will have to fill you in on that because she was here nearly the whole time.

Interviewer: You can remember that they came and did some things?

P7: They just came and that was it, you know?

Interviewer: About the people and the personalities?

P7: I can tell you very, very little. I'm quite clued up on my bowel problems and every time I have a central line, I've got a central line here, which [Local Cancer Hospital] put in and they have to come and dress all that. The first couple of weeks - this is my fourth line I've had in so you can imagine they had to come and sort all that out when it was first done. This is a new one but they're coming on Monday to take all the stitches out of that. It's all stitched.

Interviewer: Did that only go in a couple of weeks ago, did it?

P7: Three weeks ago. That's the latest one, yeah.

Interviewer: I've forgotten all the routines. I haven't done it for five years, it's disappearing at the back of my head. Okay, well if we maybe move onto when they first came to visit you with your cancer diagnosis, when was the first time the district nurses came?

P7: I can't actually remember. They seem to always becoming to see - they come in every other week to flush my lines out. Definitely, when I started on the chemotherapy they would have to come because I was on the chemotherapy with the pump on and they used to have to come and disconnect the pump and clean all the line out and everything. Now they come every other week to flush the line out because I have treatment every other week at [Local Cancer Hospital] and so they come the following week and flush the line out.

Interviewer: So it gets a weekly flush?
P7: They come every other week, they do now. Unless we need them for another reason.

Interviewer: Did they come before you had any chemotherapy?

P7: I'm not sure if they came about my bowel when I had my bowel done. [C7], again, can tell you more than I can. Memory like an elephant she has, unfortunately. She can tell you more but they've been definitely been coming for the last three years when I've had chemotherapy and everything.

Interviewer: So they've been coming to do the pump?

P7: To flush my line out, take the pump off and see to any scars and everything I've got. They would have to come when the lines first go in because they have to keep your line clear, as I say, take the stitch out of there. I've also had one in my neck here where they put the line in so they have to see to that stitching and everything. There's quite a lot of work involved and, of course, when I had this pacemaker fitted they had to come and sort all that out - redress it and all that.

Interviewer: So far you've described quite technical tasks, I suppose might be the word. Do the district nurses do other things with you when they come?

P7: They discuss if there's any bothers about my treatment or anything. They always allay my fears. One thing I am terrified is - I don't think I'm frightened of dying but I'm frightened of the nature of my death. The reason I say this is that they say, "alright, we'll give you morphine and this, that and the other to stop any pain" but I ended up in [Local Cancer Hospital] a few months ago. My line went septic, I had it taken out and put back in. I was in there for three or four days and two blokes in the beds opposite me were in agony with cancer and they were being given morphine.

This is what I said to the nurses, I said, "you know, they're in agony even with morphine, they're still in agony". They said, "we'd make sure you get fully dosed up and maybe they weren't fully dosed up or something". We don't know the situation but they've assured me that I'd be basically pain free. They're very good in giving advice on something like that.

Interviewer: When they're discussing that sort of thing, have you always found it - sorry, that's not the right way to word it. When they've been discussing that sort of thing, have you found them happy to discuss it with you?
P7: Yeah.

Interviewer: They’ve never tried to change the topic?

P7: No, never. They've always been very friendly with me. Any question I've asked, they've always answered me truthfully and I've always been happy with the answer they’ve given me. It's not just one we have, it's a team. There's about four of them and you never know which one you're getting but they're all very similar. There's none of them that have no time for you or anything, they’ve always plenty of time to spare. If I'm asking them questions, they sit down and discuss it. They're not looking at their watch, "I've got to go, next patient". They're very good.

Interviewer: Do they always just sit and talk for as long as you want? Has there ever been a time where they've had to break up and go?

P7: I don't think there is, no. I can't think of any time where they've turned around and said, "we've got to go".

Interviewer: From your point of view, how do they normally leave? Is it that you say, "I'm happy for you to go now", or do they ask, "am I okay to go now"?

P7: No, she usually says, "that’s it now, I'll see you in a fortnight" and that was it. I always laugh and joke with them. I find that's the best way of dealing with cancer, just laugh at it. Everything that goes wrong, I blame it on the chemo. [Laughs] That's the way I get round it. Some people just won't discuss it or anything but I find the easiest way is to just talk about it and laugh about it.

Interviewer: The district nurses that you speak to, you’ve got about four that come regularly?

P7: Yeah.

Interviewer: Do you have other healthcare professionals that you speak to about worries or concerns?

P7: I have been at the Macmillan care place in [Local hospital] - they phone me up and I've been there on courses of relaxation and that type of thing with them. They are periodically phoning me up asking me how I am and how am I going on and is there anything they can do for me. There's also support from there but that's the Macmillan centre. I don't think I'm ready for the Macmillan nurses yet. [Laughs]

Interviewer: So there’s the district nurses, Macmillan nurses who periodically
They're the ones in contact nearly all the time, yes.

Is there anyone else who you speak to and have regular contact with?

Only my doctor.

Your GP doctor, you mean?

My GP doctor, yeah. Of course, we see doctors and everything at [Local Cancer Hospital] every time we go to [Local Cancer Hospital] every other week. You've got to see the doctors because I'm on a special trial now. The chemo stopped working so they've put me on the trials so I had to see the doctor every week. They have to give me an examination and obviously check my blood and everything before they say I can have the trial so basically a mini medical every time I go there.

Is that different doctors?

It's a different doctor you see, yes.

Every time?

Then again, there's a team of about three so you never know which one you're going to see until we see the specialist.

I'm just wondering if you could choose a few words to describe the relationship you have with the district nurses, how would you describe it?

Being as though I've got to have them come in like I do, it's - they make it an enjoyable experience more than anything else. It's got to be done, I know it's got to be done and so they make it as enjoyable as they possibly can. They laugh and joke with you and they're talking to you all the time. No question's ever put aside. I just can't fault them for treatment, their attitude. There's never a cross word or anything, come what may. I have a repartee with them, laughing and joking with them all the time.

I've sort of sensed you prefer they didn't have to come. Is that maybe...

No, I know damn well they've got to come and without them I'd be completely and utterly lost. I can't say they're an evil necessity, not an evil necessity, they're just a necessity so
they've got to come.  I think I've got the best team I could possibly ask for.

Interviewer:  I see what you mean now, that they're a necessity and they make it the best necessity?

P7:  Exactly.  I'd be completely lost without them, I don't know what I'd do if they were awkward or anything.  They're very, very nice, every one of them.

Interviewer:  How do you get that impression that they're very nice?  What do they do to achieve that and to be like that to you?

P7:  They always come in and they're always jovial, they're always laughing away over this and that and they always call me Don.  We call them their first names.  You have to be here to see it, in actual fact, it's awkward trying to say, you need to be here to see it.  They came every other week, as I say, and I just had this put in.  I told them, "it's bleeding"...

Interviewer:  The pacemaker?

P7:  The pacemaker, I said, "it's bleeding" so straight away they said, "let's have a look at that first, then".  They hadn't come to see my pacemaker on that day.  Straight away they looked at that and saw what it was and said, "no, it'll be okay, it's just the congealed blood from after the operation" and that's what all the redness was and all the blood that was seeping out.

Interviewer:  One thing I've been asking people is about the timekeeping of the district nurses.

P7:  Now, that is one problem.  It probably not a problem - that's the wrong word, I shouldn't say that.  I've said the wrong word there, it's not a problem.  I said the wrong word there.  The only thing is they say they're coming on Monday, because they come every other Monday, and you never know what time they're coming so you're sat here waiting for them.

Interviewer:  Is that all day, or just a morning or afternoon?

P7:  Yes, you can be.  It just depends how busy they are and what their load is.  I think they try and work it so that they're doing a circular...

Interviewer:  So they're not crossing?

P7:  ...so they're not going here, there and everywhere, they try and
do a circular, each of them. Never, ever, as far as I can recollect, have they not turned up. They've always come.

Interviewer: So they've always arrived but you've often not known...

P7: Exactly what time. There's no set time for them to come, put it that way. I can't turn around and say, "yes, they come at nine o'clock every Monday" because they don't, they come when they can get round according to their circle.

Interviewer: I suppose one thing I'd like to ask is - if you had an ideal world, would you change that and how would you change that?

P7: I don't think you can change it because they never know what phone call they're going to get in the morning that's a priority so they have to put their priority before people like me who isn't a priority. It's not a priority to be flushing your line out but if someone's got - like this pacemaker, where it's burst open or something and it's pouring blood, they're a priority. They've got to come first. If I'm at the end of the list, fair enough. That's just the way it goes, but they always come. That's all that matters, they always come.

Interviewer: So you trust them that they know what else is out there and to slot you in as they see appropriate?

P7: Yeah.

Interviewer: Okay, that's an interesting view.

P7: As far as I can see, that's the only way it can work for them. Prioritise people first of all.

Interviewer: Do they ever come in on other days?

P7: Not unless we phone them and tell them there's a problem with something - then they'll come in.

Interviewer: So they haven't just popped in?

P7: I can never remember them doing that. [C7] might remember but I can't.

Interviewer: You said just now, unless you phone them. Have you contacted them?

P7: We phoned them the other week when I had this line put in. I had a line put in on the Monday morning and I had to have
treatment on the Monday afternoon the exact same day and the nurse who gave the treatment, they put…

Interviewer: Sorry, this is at [Local Cancer Hospital]?

P7: At [Local Cancer Hospital], yeah. They put a cross of Elastoplast over the entry wound. That’s the bottom one, not the neck one - the neck one is actually deep into the wound. That one there, there was a cross of sticking plaster over it. You have to watch a film of it being done so you know what to expect and everything - there was a cross. I got to [Local Cancer Hospital] and the stupid bitch in there bloody well said, "that’s in the way" and pulled it off. I thought "she shouldn’t have done that" but she’d done it by the time I realised what she’d done. She gave me the treatment and all the rest of it and I got home and it was weeping with blood. I said to [C7]. "I don’t know if they ripped the stitch out, I know it's stitched and I don’t know if they ripped the stitch out or not".

We phoned the district nurses and they said, "we're terribly busy today but, as luck has it, there is a district nurses' surgery in the clinic today, it's the one day there is one. Can you possibly get down there to help us?". It took me five minutes in the car, not even that. We said, "yes" and we nipped down and they saw to it and looked at it and said, "no, you're lucky. The stitches are still in" and they looked at it and checked it and everything. So there's that back up if we need it but I think they're only there one day a week or something, or two days. They sent me there, otherwise they would have come down, definitely.

Interviewer: So you went there because there happened to be one near to you?

P7: Yeah, or else they would have definitely come down here, I'm certain. Especially when I said to them, "I don't know if they've ripped my stitches out". They are very good.

Interviewer: That was in the daytime?

P7: Yes.

Interviewer: Have you ever had to call them out of hours?

P7: No.

Interviewer: Do you feel that you could call them out of hours? Sorry, I mean outside of working?

P7: I know what you mean, I'm just thinking about it. I think if
something was saying us to cause the district nurses out, I think I'd be more inclined to call an ambulance out because I can't think of any situation really to call the district nurses out during the night. I think it would be a major thing and I think I'd call an ambulance out, but I know they do work late at nights. I don't know about overnight but I know they do work late at night because they've said. Different shifts on.

Interviewer: So you can't think of anything that you would call them for beyond…

P7: I think whatever is trivial enough to call the district nurses out, I think it would wait until next morning.

Interviewer: That makes sense. I suppose one thing I'd like to ask you is - actually no one who I've interviewed, but people who've written about community nurses, mentioning that it changes the home environment having nurses come in. I see your facial expression there. [Laughs] Do you have any opinion on whether it changes how your home feels or what your home is?

P7: I can't honestly understand why people have said that. They're coming in to give you a service and you think it's disrupting your house? No way, no. They're coming to give you a service and do something for you - I wouldn't even call it disruption. They nearly always do me in the kitchen, it's easier because we have a bloody big box of medication we have to fetch downstairs so it's easier at the kitchen table. They used to do me in here, we found it better at the kitchen table - on their suggestion, if I'm correct. It's not a disruption at all, no.

Interviewer: Have the district nurses ever provided you with any equipment?

P7: They provide all the equipment.

Interviewer: What equipment have they provided?

P7: Having this central line in, it has to be bled and then flushed with solution and stuff. They provide everything for that, they provide all the plasters and stuff for it. They provide everything I need for my treatment. We don't go buying anything, they just provide it. The only thing that has happened is, I have medication obviously for OS and we go to the chemist to get my medication and they occasionally, very occasionally, have said, "oh, your district nurses have left this. Can you take it and save them picking it up?" but they've provided every single thing.

Interviewer: Have they provided anything other than dressings and syringes and things like that?
Interviewer: I don't know whether it's appropriate for yourself because I saw you walking just now but equipment to help around the home, that sort of thing?

P7: I'm sure it was something who sent someone around to watch me and assess me if I needed anything and a couple of things that I did have off them - one was a support for my bed to stop me falling out during the night but it was such a flaming nuisance we used it once and never again. They provided me with a water bottle for during the night if I'm thirsty, and a stool for having a shower in the shower room, saving me standing up so I could sit down and have a shower instead of standing all the time. They provided all that and I'm sure it was the district nurses who sent them to assess me and what I needed.

They assessed that and asked me if I could get up and downstairs and watched me go up and downstairs and said, "well, we don't think you're ready for a stair lift yet" so I said, "neither do I". [Laughs] Yes, they did do that.

Interviewer: Do you know what other equipment district nurses can provide, then?

P7: I don't think the district nurses can provide it, I think district nurses can suggest it and get these people down to assess you. That's the impression I got.

Interviewer: Do you have any idea of what other things you might be able to access because of the district nurses suggesting?

P7: I don't really think I need anything at this stage. Later on, when I get worse maybe, but at this particular stage I'm quite happy with what I've got because I don't believe in getting things to help you if you don't really need them. I think I try and put off the inevitable for as long as I can.

Interviewer: That's useful to know but I also meant - do you have any knowledge of what can be provided in the future?

P7: Yeah, I think so. This bloke came and was saying, "you're not ready for this, you're not ready for that, you're not ready for the other yet" which I agreed with him. I know what things are available.

Interviewer: What sort of things?
P7: Like I said, chair lifts and this, that and the other. A car, but I already have a car. Chair lifts, walking sticks and stuff. I've got my own walking stick so I don't need walking sticks. I use a walking pole from when I used to do fell walking and all that. I used to do fell walking and all that type of stuff so I've still got my walking poles. I use a walking pole instead of my walking stick because you can adjust it to exactly what you want and I find that far better.

Interviewer: To talk about the district nurses themselves - do you have any idea of what they might help you with in the future if you become more unwell? Do you have any idea how they might help.

P7: Yes, they've already told me that, as my illness progresses, they will be looking after me. That's what they said, "we'll make sure you get sufficient morphine to stop any fears you've got and if we have to come every day, so what?". They were saying that the help is always there, they'll always be there for me and they'll provide it.

Interviewer: Just out of interest, does it make a difference having district nurses saying that to you know and knowing that they're going to be there in the future rather than someone else come in when you become unwell? Does it make a difference that you think it'll be the same people?

P7: I think it makes a massive difference.

Interviewer: How so?

P7: To put it bluntly - better the devil you know than you don't know. I've got full confidence in the nurses, all the team, whereas a stranger coming in that I wouldn't know it would take a long time for me to get confident with him or her.

Interviewer: Just out of interest - how long's it taken you to build up your confidence with this team of district nurses, then?

P7: Quite a bit at first, I think. Two or three months before you got to know them and found out how easy they are and everything. You get to know the entire team and the entire team are a very, very smooth at the time. They'll all laugh and joke with you. I get the impression, rightly or wrongly, that it's their job coming round to people like me - but I get the impression that they've got to do it and so they enjoy coming around to see me. Whereas, some of the patients they say are absolute swines. [Laughs]

Interviewer: [Laughs]
They always say they enjoy coming around to see me. They say there's always a laugh and a joke and all the rest of it. I think we've built up quite a repartee between us.

Interviewer: Yeah, but that took some time?

P7: Yeah, it took a while. At first you're always nervous of anyone new, aren't you? I am, anyway.

Interviewer: Again talking about the issue of pain, because you've raised that already - would you prefer a district nurse to deal with that, one that you know, rather than a Macmillan nurse who might be specialists in that?

P7: [Pause] It's a question I've not really thought about. The only things I have thought about in that respect is that it's in my own home and not in a hospital when the time comes, but that could well be taken out of my hands depending on how bad I am and whether my wife can cope or not. There's things in the future I'm unsure about. [Laughs] As for the Macmillan nurses or the district nurses, I'd be quite happy to have the district nurses because I know them all so well.

Interviewer: Do you think the district nurses can facilitate your wish to stay at home, then?

P7: I don't know. That's what I say, it depends how severe my illness is at the end. My wife's only that big, as you can see, so if I need a load of lifting and this, that and the other, I need a lot of support in doing, and it's affecting her, then I would rather be in hospital but then it's in the future. I can't really answer that until the future comes.

Interviewer: There's maybe too many factors to...

P7: Yeah, there's too many factors involved.

Interviewer: …to know events, yeah.

P7: I just don't know how it's going to take me at the end.

Interviewer: I suppose one thing I'm interested in is - a lot of people like yourself have said they've got a small group of district nurses, you said four...

P7: About four of them, I think. Four or five.

Interviewer: Is there a number where you'd say that actually it gets too many
different people? You seem quite happy with four or five?

P7: I'm happy with four or five, I'm happy with what they are, yes. I think it could get too big if they expand it to loads of them and there's different people coming all the time. I wouldn't like that, I like it as it is at the moment. I wouldn't like just anybody who - a district nurse had been sent to see you and you don't know them from Adam.

Interviewer: You like having the same people with some regularity?

P7: Yeah.

Interviewer: So it might not be the same person one week to the next, but one month to the next you're likely to see people again?

P7: Yeah. It's always the same team of four. That's ideal to me, I wouldn't like there to be a lot, definitely, no.

Interviewer: I was just wondering whether you could tell me a little bit about the district nurses as people - what sort of people they are?

P7: I've no way of explaining that. They're always kind, they always listen to anything I've got to say. They always listen to any problems I've got, they always chat to me. I honestly can't fault them as a team or anything, they're superb. There's nothing too much trouble for them. If they come to look at these wounds around here and they say "[P7] let's have a look at it". Nothing's too much trouble for them. It's not just here they look at, it's anywhere else.

Interviewer: I know you said they were all quite similar, I'm just wondering - for example, are they all women?

P7: Yeah.

Interviewer: I'm just trying to get an idea of what - I'm a nurse but I haven't done much district nursing. I'm just wondering are they all a similar age and things? More characteristics like that.

P7: Yeah, they're all of a very similar age. I don't really know a lot about their backgrounds. As I say, they're all a similar age and this, that and the other, but I don't know much about their background. We've never really talked about their background, it's always about mine. [Laughs]

Interviewer: [Laughs] What sort of age are they then, the district nurses that come?
P7: I would say between probably 35 and 45.

Interviewer: Would you find it strange to have someone much younger or much older? Say, someone who was early 20s or in their 60s?

P7: No, no, no bother, was occasionally they'd have a young trainee with them. They didn't ever bother me at all.

Interviewer: That doesn't bother you at all?

P7: No.

Interviewer: As well, looking at their gender, would that have bothered you - if a male district nurse came?

P7: No.

Interviewer: It's just they happened to be mostly...

P7: I've been in and out of hospital so much it didn't bother me. It didn't bother me even going in mixed wards. When my aorta burst I was in a mixed ward when I went out of intensive care. I can still remember them asking me, saying, "we're taking you out of there, there's only one problem. It's a mixed ward, do you mind? Have you any preferences?". No, it didn't bother me so I went on a mixed ward then. I don't mind. Let's face it, we're in there for the same flaming thing, aren't we?

Interviewer: Well, yes. [Laughs]

P7: We've all got an illness of some sort.

Interviewer: Do you feel that there's much of a social aspect? Do you spend much time chatting about non-medical things with the district nurses?

P7: Yeah.

Interviewer: What sort of things do you end up...

P7: We chat about holidays and holidays we've had. I can't go abroad now, I can't get any insurance, so they chat about holidays to us. I used to love fell walking and that type of thing, there's another one of them enjoys walking up the hills and down so we chat to them about those things. It's not just medical matters we talk about, it's all sorts. If they've been somewhere they'll say, "we went to so and so last week". It's not just pure medical, they chat about all sorts.
Interviewer: To compare them maybe to the other people that you see - was it the medics at [Local Cancer Hospital], your GP and other Macmillan nurses that call you? Do you chat to them about non-medical stuff as well?

P7: Yeah.

Interviewer: Okay, so that's something that's common to all your healthcare encounters?

P7: Yeah.

Interviewer: Would you say it's more or less with district nurses or about the same?

P7: More with district nurses, you see them far more than your doctors. Say at [Local Cancer Hospital], there's a team of about four or so and you never know which one you're going to see at [Local Cancer Hospital]. They have a system at [Local Cancer Hospital] where they keep them for something like nine months and then they move onto another department.

Interviewer: Yeah, they rotate.

P7: They're rotating so you're never know who you're going to see and the nine months are up and the team's changing. The district nurse is here every other week for three years. You get to know them far better than a person at [Local Cancer Hospital] where you're laughing and chatting about this, that and the other, and they move on and you have to think again about the next one - what you can talk about.

Interviewer: I suppose the district nurse, obviously, can move jobs and things but it's not a planned rotation all the time.

P7: One of the nurses at [Local Cancer Hospital] who was setting me up for my chemo a few weeks ago, she said, "I was reading your notes folder, that's waiting for you downstairs" but when they phoned me for treatment and I was at the canteen. It's about the furthest place possible from [Local Cancer Hospital] to the new place. I don't know if you know [Local Cancer Hospital] now?

Interviewer: I was last there about six years ago and I know a lot's changed in six years. [Laughs] Even just the past three years, a lot's changed.

P7: They've built a new wing above the car park.
Interviewer: Yeah, I've seen it.

P7: There's the canteen - it's the furthest place to get to these things and they said, "I've been glancing at your notes while I've been waiting for you. I see you were in MRI when your aorta burst?" I said, "yeah". They said "Mr [Surgeon] did you?". I said, "yeah", she said, "I worked for Mr [Surgeon] when I was going to go on my training and everything". There's laughing and talking points of view now when she does me, "how's Mr [Surgeon]?" and this, that and the other. A talking point, like a joking point. That's the way they are, you talk about different things. I got on quite well with her when we realised we had something in common.

Interviewer: One thing I wonder is how much time is spent chatting about the non-medical stuff and how much is spent chatting about the medical with the district nurses?

P7: Not really much chat about the medical side of it because they just come and get on with it. I don't have to send them to the house and say "I need you to do this" I'd have to do everything backwards. They just come and do it and just chat to them about the time of day, what horrible weather it is, wish the snow would, or went to [Local Town] the other week, and this, that and the other. It's just general chat with them because there's nothing really to talk about medically unless I've had some problem, such as here.

Interviewer: How long do the visits usually last then, on average?

P7: I'd say a minimum of 20 minutes. It takes them 20 minutes to flush the line out and do everything, but you can never tell. I had a PICC line in, which goes in your arm, the latest treatment I had. After my line coming out, I had this new treatment and I came out in spots all over me, terrible spots everywhere, and they were all postulated. They couldn't put my central line in. They said, "we daren't put one in" so they put one in my arm. They were bending my arm and everything and it kinks the thing so it's just not satisfactory. One day, the district nurses - two of them came.

One of them came and she couldn't bleed it so she phoned for one of the others to come, one of the senior ones, so she came down. There was two of them here trying to bleed it, trying to get blood flowing, and they struggled. They phoned [Local Cancer Hospital] and talked to [Local Cancer Hospital] about it. They said, "leave him until his next treatment and we'll sort it out when he comes down". They must have been here for nearly an hour and a half. It must have been the way it was struggling trying to get blood and phoning [Local Cancer Hospital] and asking their advice and everything else. You just can never tell.
Interviewer: On average, it's been about...

P7: On average, about 20 minutes, half an hour. Talking about the PICC line, when I went to [Local Cancer Hospital] they couldn’t do it so they had to take it out. That’s why I've got a central line in.

Interviewer: I've always found PICC lines a bit - as you say, because they're in your in your arm they kink but when they go in there there's nowhere really for you kink them.

P7: The consultant, Dr [Local Cancer Hospital Consultant], he didn’t want me to have one but my chest was all these pustulated spots everywhere and he just said, "we can't put one in there, we daren't" and that's why they put the one in my arm. He was quite happy when I got one put back in my chest because he said, "I don't like PICC lines".

Interviewer: Is there anything else that the district nurses do when they come that you think, "oh yeah, that gives me good quality to my care. It's more than just coming and doing the line" - is there anything else that they do?

P7: I can't think of anything. They instil confidence in you though because you discuss with them things that might go wrong.

Interviewer: They what, sorry?

P7: When they discuss things like - fears about always allaying them. They're very good.

Interviewer: That's some very interesting points there. Some really interesting ways of looking at it. Thank you very much.

P7: Anything you want to ask me?

Interviewer: I've asked you quite a lot, I think. [Laughs] What I've done with most people is I go away and type the interview up and I usually ask if I can come back about a month later because often when you sit down and you're really reading it, you think of other things, "I should have asked that or I should have asked that". If that’s okay?

P7: Of course it is, of course.

Interviewer: Okay, well shall I go and find [C7], yeah?
End of recording