Patients’ and family carers’ construction of quality in supportive and palliative district nursing care

Report for Dimbleby Cancer Care Trust
Catherine Walshe, Maurice Nagington, Karen Luker,
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Acknowledgements

The authors of this report wish to thank Dimbleby Cancer Care and the University of Manchester Alumni Fund for funding this project and all individuals who helped facilitate this work. We were very grateful for the time given by healthcare professionals and research nurses who recruited participants to the study. Thanks must also go to the research advisory group who helped guide the project and focus on patients and carers needs right from the beginning. In particular we wish to express deep gratitude to all the patients and carers who generously gave their time and offered open and honest discussions about not only their experiences of district nursing care.
Executive Summary

Background
District nurses are seen in practice and policy terms as central to the provision of palliative and supportive care at home. Understanding how to maximize the quality of the care they give, and improve satisfaction with care received from them is therefore important. Whilst research has examined professionals’ perspectives on the quality of palliative and supportive care at home, little has been done from patients’ and carers’ perspectives. Exploring this topic from patients’ and carers’ perspectives is timely because an increasing emphasis is being placed on palliative and supportive home care and incorporating patients’ and carers’ views into healthcare provision.

Aim
The aim of this research project was to explore patients’ and carers’ constructions of quality palliative and supportive district nursing care, and where appropriate to explore how constructions of quality varied between patients, carers, and different socio-demographic groups.

Methods
In–depth interviews were conducted with 26 patients and 13 lay carers across the North West and the West Midlands of England between September 2010 and October 2011. The data were analysed using a combination of thematic and discourse analysis techniques.

Findings
This was a qualitative study with 26 patients and 13 carers with a varied demographic (see table 1 and 2 for demographic data). In general demographic factors did not seem to influence patients’ and carers’ views on quality. Across all the demographic variations patient and carers viewed district nurses as primarily
concerned with the physical care needs of the patient. This contradicts the views of district nurses who report giving ‘holistic’ care (particularly in the form of early support visits before any physical care needs are identified) such as psychological and social support.¹

Table 1: Patients’ characteristics

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<td>Diagnosis</td>
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<td>Malignant = 19</td>
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<td>Non-malignant = 6</td>
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Table 2: Carer’s characteristics

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</tr>
<tr>
<td>Mean = 68</td>
</tr>
<tr>
<td>Range = 58 – 79</td>
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</table>

There were two main reasons identified for this discrepancy: patients’ and carers’ perception that district nurses were busy; and that patients and carers lacked knowledge of district nursing services and therefore what was possible in home care.

The only demographic which did influence perceptions of quality was patients with no regular lay carer(s) (n=2). In these cases patients highly valued district nurses implementing short ‘check up’ visits which were not focussed around physical care.
Busyness

This report suggests that busyness results from a culture of targets and measuring with the end goal of achieving efficiency.\(^2\) In addition increased workloads\(^3\)\(^5\) may also impact on the busyness of district nurses as perceived by patients and carers. Two themes demonstrate the effects of busyness:

- Patients recognised that they had additional support needs, but ‘self-policed’ their expression of needs by not reporting them to their ‘busy’ district nurse.
- Where district nurses conducted themselves in a way that fostered friendships and/or did not appear busy it was possible for patients to experience valued aspects of care beyond physical interventions.

For quality care to occur there needs to be a move away from measuring in order to reduce busyness. Whilst a small number of metrics may still be required for public accountability (i.e. mortality rates), in general measuring focuses district nurses on a narrow set of targets to demonstrate efficient care is occurring this may result in individual patients’ needs going unexpressed. In addition district nurses’ increased workloads are likely to contribute to patients and carers perceiving district nurses as busy.

Knowledge

Patients and carers often lacked knowledge of what district nurses could do for them beyond the predominantly physical care which they were already receiving. There were also no means for patients to develop knowledge about district nursing services other than by experiencing them.

The home

District nurses were highly valued for the role in which they played in maintaining patients. However, even though the value of the home for patients is recognised by district nurses in research literature and policy, patients reported that the home was often considered an unsuitable care environment because optimal medical care could not be given. There were no examples of district nurses advocating patients’ and carers’ views to remain at home for medical care. There were also very few
examples of alternatives to hospital care being discussed and put in place to support patients at home when medical problems arose.

Policy implications

The views of patients are beginning to be central tenets in healthcare policy. This report discusses some of the problems that remain with integrating patients’ perspectives into palliative and supportive care provision, such as:

- All the concepts expressed in recent policy documents in relation to district nursing take the district nurses’ viewpoint as the way to assess how care is given.
- ‘Right care’ remains defined by medical and district nursing ideas rather than in collaboration with patients and carers
- Patients and carers are conceptualised as someone to ‘assess’ or achieve the right care for, not with.

This report also highlights the poor development in both policy and practice of involving carers in service provision. Some of the key policy implications are as follows:

- The views of carers in policy developments are completely absent despite recent healthcare legislation and policy mandating their inclusion.
- A lack of carer inclusion is reflected in the empirical data of this project where carers were often utilised and trained for the benefit of the patient and were rarely the subject of assessments and care for themselves.

In addition many recent policies have aimed to re-organise district nursing to make it more efficient. The empirical data gathered in this report did not directly assess district nursing workloads. Therefore, no direct link can be made between perceived busyness and increased workloads. However, it is important that policies which aim to reduce or re-organise district nurses to create more efficient systems of care take
into account how any increase in workload might negatively impact on the quality of district nursing care.

One of the solutions to reducing the perceived busyness of district nurses may be to increase the number of district nurses. This has obvious cost implications which go beyond the scope of this report. However, the negative effects of busyness could also be reduced without any increased costs by decreasing and eliminating a culture of measuring where achieving the target becomes the proxy for quality.

Clinical implications

The implications of this study broadly fall into two categories. Findings that can be implemented by service managers and those that need to be implemented by individual district nurses.

Managerial implications

- District nursing services should explore appropriate ways in which they can proactively distribute information on service provision, including but not limited to: support visits for both carer and patient, psychological support, and equipment provision.

- Information sheets are developed (with the involvement of patients and carers) which inform patients about the role of district nurses in their area including specialist nurses. It may be appropriate to broaden this out to community services in general with a specific focus for palliative and supportive care.

- District nurses are allocated enough time for patients, carers and to discuss and understand their district nursing services. Reviews may be necessary for patients whose needs change over time.

- The increase in district nursing caseloads needs to be monitored and published. This study cannot make a direct link between the increased workloads of district nurses and the quality of care as workload data was not collected, nor is any such data available in national statistics such as the former health trends data. However, it seems likely that the quality of care may be negatively affected when patients perceive district nurses as ‘busy’.
**Individual district nursing implications**

- Greater attention must be made towards supporting carers. The empirical data in this study suggests that carers recognise the primacy of caring for the patient, but also highly value small amounts of dedicated time from the district nurse for themselves. Where this does occur there is limited evidence to suggest that it results in extra support services (not provided by district nurses) being put in place for the carer.
- District nurses are encouraged to interact with patients and carers in relation to more than their physical illnesses. In some cases this may mean interacting with patients in a way that is akin to a friendship or a counsellor. When this occurs patients and carers are more able to discuss their individual needs with district nurses. To be clear this report does not mandate such interaction, it is merely encouraging a permissive approach to the ways in which district nurses may wish to interact with their patients beyond their physical healthcare needs.
- District nurses must discuss and advocate patients’ and carers’ views on remaining at home. In particular district nurses have a role in helping patients and carers discuss the potential advantages and disadvantages to home care versus hospital care; where necessary acting as advocates for these preferences.

**Future research**

Further research is suggested in the following areas:

- Exploring from patients and carers’ perspectives the most appropriate style, content and format of information leaflets.
- The relationship between the quality of care and district nursing workloads.
- Other means of distributing information should be explored for their utility in this patient/carer group such as: online forums, social media, and expanding current systems such as NHS choices to allow feedback to be given on district nursing services.
Exploring in more depth the views of specific socio-demographic groups, in particular BME, LGBT and working class individuals.

Conclusion

Whilst the above implications for policy and practice may make it appear that the quality of district nursing is variable it must be noted that with only one exception patients and carers valued their district nursing service. In particular patient’s highly valued their role in facilitating their continued care at home. This report notes that district nurses provide a wide variety of care to patients and carers with palliative and supportive care needs under increasing political, financial, and workload pressures. The current culture of measuring to ensure quality of care coupled with increasing workloads appears to result in the production of a busyness which negatively affects the quality of care from patients’ and carers’ perspectives. In addition patients and carers often lacked knowledge about district nursing services resulting in care occurring in hospital even when there are clear preferences for home care.

If quality of care is to remain stable or improve the above issues must be addressed. This report suggests ways in which this could be achieved without increasing spending on district nursing services such as eliminating measuring. However, it also highlights that decreasing district nurses’ workloads by introducing additional staff may be appropriate if future research can demonstrate a clearer link between workload, busyness and quality of care.
Section 1: Introduction

1.1 Introduction

This report presents the findings of a three year qualitative research study investigating the perspectives of patients and carers with palliative and supportive care needs on the quality of their district nursing care. There were three aims to this study:

1. To understand patients’ perceptions and definitions of what constitutes quality district nursing supportive and palliative care provision and outcomes.
2. To understand co-resident family carers’ perceptions and definitions of what constitutes quality district nursing supportive and palliative care provision and outcomes.
3. To explore variations in such perceptions and definitions in different patient groups, and between patients and carers.

The following report presents the findings of this research study in relation to these three main aims.

1.2 Research team

The funding made provision for a PhD candidate and the research team consisted of Karen Luker (KL), Catherine Walshe (CW) and Maurice Nagington (MN, PhD candidate). Maurice Nagington conducted all interviews and initial analysis. Prior to and during the research project MN received a variety of research training as part of

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1 Co-resident family carers will be referred to as just ‘carers’ for the remainder of this report. In addition a very broad understanding of ‘family’ was applied which included close friends but excluded professional carers.
his PhD programme. Regular supervision and peer review of the research was carried out by KL and CW. The PhD was awarded in December 2013.

1.3 Background

International policy in developed countries concerning palliative and supportive care has increasingly argued for patients to have choice in relation to service provision\(^6\) and specifically for there to be the choice for care to occur at home\(^10\). Research investigating palliative and supportive home care has primarily examined the perspectives of professionals\(^11\) and lay carers.\(^12\)-\(^13\) Research from patients’ perspectives, specifically relating to district nursing care (as opposed to primary care in general) is limited.\(^14\)

1.3.1 District nurses

In the UK district nurses are the single biggest provider of care at home for patients with palliative and supportive care needs.\(^15\) Reviewing some of the contemporary literature about district nursing in relation to quality in palliative and supportive care it appears that district nurses claim palliative and supportive care is ‘different’ and that it is one of the last remaining areas where ‘holistic nursing’ is practised.\(^16\)-\(^18\) It is clear that district nurses form a key role in community palliative care performing roles of assessment, personal care, emotional care, and care co-ordination.\(^14\)-\(^15\) It has been suggested that much of this ‘holistic’ care occurs in the form of ‘early support visits’.\(^1\)\(^19\)-\(^20\) District nurses seem to hold these visits as highly important for non-physical care and relationship building\(^11\) but it has been argued that these aspects of district nursing care are ‘invisible’ and go unaccounted for.\(^21\) However, observational data of district nurses in practice questions the extent to which some of this support is given,
in particular psychological support with examples of district nurses avoiding discussions around psychological distress.\textsuperscript{22} In addition to caring for the patient's needs, district nurses also have a role in providing support for carers. This is something which is claimed to contribute to the quality of care in the accounts of district nurse,\textsuperscript{23} and also the retrospective (post patient death) accounts of carers.\textsuperscript{13} However, again observational data has failed to find the same high quality care occurring as suggested by the interview studies.\textsuperscript{24}

It appears to be uncontested that district nurses can and do play a central role in the provision of palliative and supportive care. However, there is a lack of clarity in the literature, particularly in relation to what patients perceive as contributing to the quality of palliative and supportive district nursing care.

1.3.2 Quality of care

Quality of care can be defined using four perspectives:\textsuperscript{25} professionals, managers, service users, and funders. Each of these differing perspectives influences how quality of care may be defined and evaluated and hence how it may be improved.

*Healthcare managers*

The funders of healthcare and health care managers have received extensive criticism internationally for treating healthcare in the same way as any other industry.\textsuperscript{10, 26} It has been argued that a shift has occurred where cost effectiveness and efficiency have encroached upon and in some cases become euphemisms for quality of care.\textsuperscript{27} A similar criticism was made in the Francis Report\textsuperscript{28} where it was argued that a focus on financial targets was one of the key causes of inhumane care occurring on hospital wards at Mid Staffordshire NHS Trust. Whilst good financial
governance is logically key to the running of any organisation within modern western societies, financial metrics become problematic when assessing aspects of quality such as compassion and comfort. Therefore, whilst healthcare management may be important to the running of a good organisation, to conflate this with quality of care may be erroneous.

*Healthcare professionals*

Professionals’ perspectives have been frequently utilised in assessing the quality of care. Whilst nurses’ perspectives often incorporate the idea of ‘emotional labour’ and ‘psychological support’ into the concept of quality care, these understandings are often seen as ‘alternative’ to constructions based on biomedical ideas. This can often lead to professionals’ conceptions of quality of care being represented as primarily concerned with medical matters. There are very few examples of NHS trusts publishing metrics on the quality of palliative and supportive care from any perspective and the ones that do tend to focus on metrics concerned with physical well-being. For example, The University Hospitals Birmingham NHS Foundation Trust suggests ‘quality’ in palliative and supportive care is measurable by the prescription of opiates and laxatives. Whilst such medical prescribing is undoubtedly important in palliative and supportive care, professional perspectives dominated by medical ideas may be limited in their utility in palliative and supportive care because they fail to account for valued aspects of care such as psychological support.
Funders

Healthcare funding in economically developed countries has two significant contributors, private funding via private insurance or individual direct payments, and state funding via taxation. The source of funding has considerable impacts 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 their customer base whilst remaining profitable and competitive on an open market. State funded systems on the other hand attempt to balance fiscal limits with providing the best care for the greatest number of people. However, since the 1970s free market reforms have played an increasing role in balancing costs with quality of care. However, the evidence for the effectiveness of free market reforms as a strategy to achieve quality of care is lacking and appears to be more political rhetoric rather than evidential arguments. For example, American healthcare, which is still largely based on a free market system, costs the most per capita GDP costing approximately double any other comparable country with no better (and in comes cases worse) health metrics. These problems aside, it is possible to observe that free market approaches to healthcare create a consumer culture which alters the measures used to assess for quality of care. In the UK policies have begun to include patient orientated outcome measures, alongside the traditional medical measures such as mortality statistics and surgical recovery times, to allow for more of a focus on patients’ experiences such as having a quiet night time environment.

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ii A more detailed discussion of this can be found in Auerbach and Kellermann (2011) but in brief America spends 17.8% of its per capita GDP on healthcare and achieves an average life expectancy of 78.6 years; the UK (with similar population demographics) in contrast spends only 9.3% and achieves an average life expectancy of 80.7 years.
Patients and carers (or consumers)

Whilst the move to include patient led outcomes may be valuable there is little evidence that patients base their choices on these new forms of patient outcome metrics. In relation to district nursing there are no nationally available metrics (patient focussed or not) nor can patients choose their district nurse. Therefore, whilst patients’ and carers’ perspectives may initially appear valuable in measuring and developing quality of care, if choice does not exist, then the free market systems put in place to improve quality of care are relatively powerless to enact change.

Relational quality of care

It is also possible to consider quality of care in terms of how individuals interact. Nagington et al\(^2\) suggest quality of care is commensurate with allowing and encouraging interactions between professionals and patient to be characterised as allowing individuals to develop their identities in novel ways such as developing friendships; as opposed to being purely based around a specific set of extant ideas such as cost effectiveness, medical outcomes, or research based patient outcomes.
Section 2: Research Methods

2.1 Methods

From the above literature review it is apparent there was a gap in the literature pertaining to patients’ and carers’ views on the quality of palliative and supportive district nursing care. Therefore, this research study explored patients and carers’ views utilising qualitative semi-structured interviews.

2.2 Ethics

All appropriate ethics and research and development approvals were secured for this project. Formal ethical approval was granted by the Northwest 8 NHS research ethics committee (reference 10/H1013/3).

2.3 Sampling

Clear inclusion and exclusion criteria (see box 1) were established in order to recruit an appropriate sample that could inform the research questions.

**Box 1 – Inclusion/exclusion criteria**

<table>
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<tr>
<th>Inclusion criteria</th>
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<tbody>
<tr>
<td><strong>All participants</strong></td>
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<tr>
<td>Over 18 years old</td>
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<tr>
<td>Able to consent</td>
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<tr>
<td>Able to participate in an in-depth interview</td>
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<tr>
<td><strong>Patients only</strong></td>
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<tr>
<td>Receiving or requiring palliative or supportive care</td>
</tr>
<tr>
<td>‘Active’ on a district nursing case load</td>
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To prevent potential coercion in the study it was decided that none of the participants should have any previous relationship with any of the research team prior to being recruited to the study. If participants came into contact with any of the research team after being recruited to the study (i.e. in MNs role as a staff nurse at a local hospice) a third party was asked to confirm that they were happy to continue contact in this different capacity.

2.4 Recruitment

Participants were recruited between September 2010 and October 2011 in five community healthcare trusts via district nurses and other specialist community nurses (i.e. palliative care nurses and heart failure nurses), and via research nurses and hospice staff in five hospices. All recruiting professionals were asked to hand information packs (appendix 1 for patients and 2 for carers) to any patients who fulfilled the inclusion and exclusion criteria (box 1), approximately\textsuperscript{iv} seventy five recruitment packs were distributed. Thirty one patients responded, one was ineligible due to him feeling his disease was not palliative, and four patients became too unwell to be interviewed. This resulted in a sample of twenty six patients, thirteen of whose carers were also recruited.

\textsuperscript{iv} This is an approximate figure as on some occasions healthcare staff were either uncertain about the number of packs handed out, or left their jobs during the data collection period and could not be contacted.
2.5 Data collection

Data were collected using semi-structured qualitative interviews (see box 2 for topics covered) three cases\textsuperscript{*} were interviewed twice (P6, P7, P12). The low number of repeat interviews is due to the high morbidity and mortality rates experienced in palliative and supportive care.\textsuperscript{44} All interviews were audio-recorded, professionally transcribed and then checked for accuracy before being entered into NVivo (a qualitative data management programme). Interviews were not reviewed with participants for accuracy, again due to the high rates of morbidity and mortality.

Data were collected in a variety of settings depending on participants preferences, venues included: participants’ homes, University premises, and hospice day care centres. 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.

\textsuperscript{*} A case includes either just a patient or a patient and a carer
The interview protocol went through three iterations (see appendix 4, 5, and 6 respectively for details of the protocols used) using thematic analysis as described in grounded theory.\textsuperscript{45} The first iteration of the interview protocol was developed by reviewing literature and discussion with a research advisory group. Subsequent iterations were developed by reading transcripts and assigning themes to sections of data. If themes emerged multiple times or were particularly relevant to the research question they were added to subsequent protocols. For example, ‘previous contact with district nurses’ quickly emerged as a theme which recurred in the interviews and was added to subsequent interview protocols for further investigation. A summary of the topics covered across all interviews can be found in box 2.

2.6 Data saturation

The concept of ‘data saturation’ was used to establish when data collection should cease. Traditionally data saturation is considered to occur when the same themes continue to occur during data collection with no new themes emerge (a full list of themes used in the substantive analysis can be found in appendix 6).\textsuperscript{46} However, within this study saturation was considered to occur when the reasons for why these themes were stable had been established.\textsuperscript{47} For example, themes around extant understandings of 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 why participants perceived district nurses in this way and what resources were available to them to develop and change their knowledge of district nurses.
Box 2: Summary of interview topics

<table>
<thead>
<tr>
<th>Summary of interview topics</th>
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<tbody>
<tr>
<td>General experience of district nurses</td>
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<tr>
<td>Relationship with district nurses</td>
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<tr>
<td>Time keeping of district nurses</td>
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<tr>
<td>Experience of care at home</td>
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<tr>
<td>Continuity of district nursing</td>
</tr>
<tr>
<td>Previous contact with district nurses</td>
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<tr>
<td>Previous knowledge of district nurses</td>
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<tr>
<td>Discussion of district nurses with others</td>
</tr>
<tr>
<td>Use of touch by district nurses</td>
</tr>
<tr>
<td>What do patients do for district nurses</td>
</tr>
<tr>
<td>Information sheets about district nursing</td>
</tr>
</tbody>
</table>

2.7 Discourse Analysis

Once thematic coding for protocol development and data saturation occurred the themes were analysed using discourse analysis techniques. There are no hard and fast rules on how to undertake discourse analysis.48-51 However, some broad questions have been put forward by O’Connor and Payne50 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?
Therefore, discourse analysis involved reading passages of text, examining what underlying concepts and assumptions were circulating and how they functioned to shape the participants’ constructions of quality.
Section 3: Results

The three key research questions addressed in this report can be found on page 10. This section begins by exploring the sample’s demographics, in particular the difference between patients who do and do not have a lay carer. This is followed by presenting the data on how carers and patients differentially construct quality. Finally, three of the most influential and overarching themes are presented which occurred in the data irrespective of any demographic factors, namely: busyness, knowledge and the home.

3.1 Introduction to sample

A summary of the patient (table 1) and carer (table 2) characteristics can be found below (individual participant’s demographics can be found in appendix 7. When presenting qualitative data patients and carers are given unique code names in the form of P and C respectively. The low number of carers taking part is due to two patients either having no lay carer to interview (n = 2) or carers declining to take part in the research (n=11). This is not considered problematic for this study as one of the primary gaps in the literature was exploring the patients’ perspective, therefore it would have been inappropriate to decline patients to participate if their carers were unwilling.
Table 1: Summary of patient characteristics

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Table 2: Summary of carer characteristics

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<tr>
<td>Age</td>
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</tr>
<tr>
<td>Mean = 68</td>
<td>M = 6</td>
<td>White = 13</td>
<td>Yes = 12</td>
<td></td>
</tr>
<tr>
<td>Range = 58 – 79</td>
<td>F = 7</td>
<td></td>
<td>Undisclosed = 1</td>
<td></td>
</tr>
</tbody>
</table>

The sample’s demographics contained a spread of different ages, genders, diagnoses, ethnicities and marital status’. In relation to the third aim of this study (to explore variations in such perceptions and definitions in different patient groups, and between patients and carers) the variation expressed within these demographics is explored below. However, it should be noted that the analyses of the variation between the different demographic groups are limited by the numbers recruited to enable rigorous comparisons to occur. In relation to the majority of the demographic factors, little variation could be observed. For example, patients with a malignant diagnosis had similar understandings of how district nurses could help them at the end of life, to those with non-malignant diagnoses as indicated in the extracts below::
“Interviewer: So are there any things that you think the district nurses might…help you with in the future?

P19: No, I don't think so, can't think of anything. [pause]... if I'm not so well, they'll contact the doctor for me… yes, with doing my legs, yes. Looking after my legs and I think yes, definitely keep me out of hospital with my legs.”

(P19, Male, 50, COPD)

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“Interviewer: Okay. Are there any other things that you think they [district nurses] might be useful for in the future…

P5: I can't think of anything besides equipment, you know.”

(P5, Female, 75, Ovarian Cancer)

Whilst not initially appearing similar (i.e. one patient with cancer cites equipment provision and another with COPD cites assistance with leg dressings) neither patient is able to conceptualise that district nurses may be able to help with their supportive and palliative care needs at the end of life. This is despite both patients being aware of the palliative prognosis of their illness. Their accounts are therefore similar in their omissions of how they can conceptualise district nursing care. Similarly in this data set age, gender, and race did not have any discernible impact on patients' and carers' constructions of quality palliative and supportive district nursing care.
**Full time lay carer versus having no lay carer**

Having a full time lay carer (either spouse or child) differed from the other demographic factors in that there was a notable variation in the way that patients with full time lay carers interacted with district nursing services:

“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… if he’s (P6) taken ill… the district nurses have told me to… give him his nebuliser, he has oramorph, 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.”

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“P18: I always assumed they [district nurses] bore the brunt of everything which, of course, they do, they’re at the sharp end of everything now… there’s a lot of things dispensed to them now, particularly now that…it was the doctor’s responsibility initially but, of course, the role of the doctors has changed as well.

*Interviewer:* Yeah. So when you say bore the brunt, bore the brunt of what?

*P18:* Well, of the care, of the complete care, which involves everything, dressings, etc, treatment, everything to do with whatever, I have them three times a week now, at this point… they’ve [even]
turned up to check dressings on a Sunday, that’s been happening…

They’ve identified many things recently. For instance, they identified, when they were dressing my back, that I’d got another infection so I was instantly put on antibiotics…”

Therefore, it can be seen that having in the case of P6/C6 the spouse assumes a large amount of training and responsibility within the home environment for monitoring and maintaining the ‘patient’ at home. This results in district nursing visits occurring “every few weeks”. However, in the case of P18 who had no close relatives or spouse living nearby it can be seen that district nurses visit to “check up” on the patient and that during such visits important clinical needs are detected such as infections which allow earlier interventions to take place.

3.2 Patients’ and carers’ differential constructions of quality

In relation to the second aim of this research project to investigate carers’ constructions of quality there were very limited examples of carers’ constructions of quality differing from patients. Therefore, the data for patients and carers is presented together organised under three of the core themes that emerged during data analysis: busyness, knowledge, and the home. These themes were selected for a key interlocking reason: that they all had significant and wide ranging effects on quality of district nursing practice. Other auxiliary themes (listed in appendix 6) are used to demonstrate how the core themes function throughout this report. Where differences between patients’ and carers’ constructions of quality do occur, these are highlighted in the appropriate sections and explored further in the discussion section.
3.3 Busyness

This section explores how busyness shapes patients’ and carers’ approaches to their district nurses, subsequently affecting the quality of care. Friendship as a theme is also presented as a counter example of how care can be affected by the ways in which district nurses interact with patients and carers.

3.3.1 Effects of busyness

A sense of busyness was often closely tied to an understanding of how district nurses managed their time:

“P18: There's no way they can commit themselves to any length of time… I've said, jokingly, oh, you're running a bit behind today! [The district nurses say] 'we've been very busy, we've had an emergency or we've had this happen'.”

Busyness therefore from the patient and carer perspectives becomes a reason for why patients and carers were unable to secure an accurate timeslot with district nurses. However, its effects were wider ranging:

“P5: I know they do a good job and they're busy… I always say, ‘You know, do you want a drink or something?’… I think it’s only once when [district nurse] had a drink off me.”
It can be observed that busyness also begins to direct not only the structuring of when district nurses visit, but also the types of activities that district nurses engage in:

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

P16: It would be a confidence builder, yeah. But that’s all… it would take too much 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.”

The expectation of a busy district nurse means that patients and carers are reluctant to ask for additional care from district nurses because they perceive district nurses as ‘being busy’. The effect of busyness preventing care taking place also affected physical care:

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

Therefore it can be observed that ‘busyness’ is a reason for district nurses not to conduct a wide range of care which patients were currently receiving, or currently needed. However, the effects of district nurses being perceived as busy was not
limited to the present, it also extended to patients’ and carers’ conceptualisations of future care:

“Interviewer: … in the future… 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.”

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“Interviewer: 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…”

The first quote (abbreviated to just the carers voice for brevity) demonstrates that patients and carers have clear ideas about aspects of care which they desire to see undertaken by district nurses. However, these ideas are curtailed as being a possible future reality because district nurses are perceived as ‘being busy’. The second quote appears to suggest that busyness does not have the all pervasive influence that is suggested from the first quote. At first it appears to suggest that patients and
carers believe district nurses can and will provide additional care. However, such a reading would be premature and other data suggests an alternative reading:

“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… 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…

P25: Like bedfast or anything like that, I know.”

Taking this third quote into account we can see that the statement of P17 “I'm sure if we needed help they would help us… If we need them they come, if we want anything…” is questionable because the data from C25/P25 makes it clear that ‘anything’ can lead to an uncertainty because of a total lack of limits. This lack of limits affects district nursing care. Patients and carers do not challenge and explore
their care because they perceive district nurses to be busy. Through this lack of challenge patients and carers never come upto the limits of what district nursing care can provide and district nursing is perceived as a quality service because district nurses are constructed as ‘doing anything and everything’.

3.3.2 Friendship

Not all district nursing was characterised by busyness and its negative effects. There were multiple examples where patients and carers were able to develop their care in ways which benefited them, one of the key themes that influenced this was friendship:

“P1: When I did start to need them the Sister came out… they observed my wife doing a drain and they were quite happy to leave her to it… they came back a few more times to observe…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… 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… without upsetting me or the wife.”

This quote demonstrates how friendship allows patients and carers to further explore how their district nursing care may develop. However, whilst the affective quality of friendship is valuable, and produces an ethical action by virtue of allowing patients
and carers to develop as friends not just remaining patients, the effect it has on developing care is limited:

“Interviewer: 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… not friends like friends that you go out with but… you feel like you can kind of tell them things and, if you're not feeling so good… 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… maybe speak to the doctor… you’ve built up that kind of personal relationship.”

Whilst a valuable relationship is built up in these cases, friendship only conveyed a feeling of being able to talk. It did not convey what may be talked about, or the type of support that district nurses could offer.
3.3.3 Summary

These data suggest that when district nurses either act or claim to be busy it may have a negative effect on the way in which patients’ and carers’ can develop their understandings of district nurses and the care that they can receive. Friendship, whilst conveying a feeling that patients and carers can approach their district nurses for additional care, fails to convey any knowledge about what district nurses may be able to do.

3.4 Knowledge

This section explores the knowledge that patients and carers have of district nursing palliative and supportive care. Knowledge about palliative care services has previously been suggested to be important for patients and carers in order to prevent negative misconceptions about the role of palliative and supportive care\textsuperscript{52-53} and to enable patients and carers to navigate the care system.\textsuperscript{54} However, the effects of knowledge have not been explored from an ethical point of view in relation to how care may or may not develop for patients and carers.

3.4.1 Knowledge of district nursing

In order to understand how knowledge of district nursing develops it is necessary to understand what patients and carers knew about district nurses before they had contact with them. When asked what district nurses did, two key themes emerged from past experiences and media representations. Personal care involving hygiene needs and care which required more training such as around dressings:

\textit{“P2 bath people in bed and things like that, you know”}
“P4: I just thought they went around dressing wounds.”

These understandings of district nursing did not develop when patients and carers initially met their district nurses:

“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.”

When district nurses met with patients there were no reports of patients or carers remembering any discussion on the broader services district nurses provided such as psychological support. There were limited examples of such care occurring:

“P12: 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.”

However, patients and carers did not raise psychological support issues with district nurses themselves. Instead they lacked knowledge about this aspect of service provision:
“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.”

Hence, whilst some patients received timely support from district nurses, others did not. Psychological care for carers was also inaccessible:

“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…”

It appears that carers’ knowledge of district nurses as having a role in supporting carers was also limited. Therefore any psychological care was also generally inaccessible to carers because of the double bind of district nurses being perceived as concerned with patients and physical care.

3.4.2 Knowledge of Future care

A lack of knowledge about district nursing care also extended to potential future care which patients and carers may require:

“P24: I think their role…I’d hate to say their [district nurse] role be expanded…but I think, like myself, not knowing that they do certain things… [decreases] people’s ability to access the things they have.”
In addition to preventing access to care at times this lack of knowledge produced anxiety and uncertainty:

“P24: Is somebody going to tell me that that’s what happens? I think is somebody going to tell me once [local cancer hospital] 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… it’s just things that do go through your mind.”

It would appear these empirical data demonstrate that a lack of knowledge around service provision produces anxiety; whether such lack of knowledge occurs because of an active or passive avoidance of discussing service provision is unclear.

3.4.3 Developing knowledge

In the final three interviews patients and carers raised a possible way of increasing knowledge of district nursing services:

“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.”

An information leaflet about district nursing palliative care services (or possibly community palliative care services as a whole) would appear to be a none distressing way of distributing knowledge. These conclusions need to be treated with caution as information leaflets were only discussed with the last three participants. However, it should be noted that there were no reports of distress occurring in response to the patient/carer information leaflets which were handed out to approximately seventy five patients.

3.4.4 Exchanging knowledge

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:

“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 because it was prompted by the research project. However, it demonstrates that once conversations begin to occur between patients it is easier for them to critique practice which had up to that point been the status quo and uncritically accepted.

3.4.5 Summary
This section demonstrates that a lack of knowledge contributes to the inability of patients and carers to develop their care and that power to direct care remains primarily with district nurses. Where knowledge is distributed to patients and carers, it is limited to the care which they are already receiving and does not facilitate any thought around future care or facilitate patients and carers expressing their needs. These empirical data suggest that written information (in particular leaflets) about district nursing services in relation to palliative and supportive care could be beneficial. It also suggests that carers’ knowledge of district nursing focuses on the role that they play in caring for the patient, not the carer.

3.5 The home
The home, almost without argument, is tied to the functioning of district nursing and there have been several research projects exploring how nursing functions in the home. However, all these research projects have assumed that ‘the home’ is a
fundamental somehow fixed point of reference which can be written in reference to how nursing changes ‘the home’. This report makes a different assumption; that ‘the home’ is a discursive and material entity which is constantly being performed and maintained. To put it another way, the home is what people claim to say and do in relation to ‘the home’. Therefore, in this analysis district nurses are assessed for how they become involved in the performance and maintenance of ‘the home’ and there is no assumption that this is intrinsically positive or negative. However, before this can be discussed, the conditions under which district nurses enter the home must be explicated.

3.5.1 Inevitability of district nurses for home care

The way in which district nurses are the inevitable provider of physical care was reflected in all interviews with the exception of one patient received their initial visit from a district nurse for non-physical care reasons. The support visit for this patient resulted in a broadly unsuccessful visit:

“Interviewer: Just to talk about that initial meeting… 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… whatever else they said, I don’t know, because I latched onto a note… saying ‘in the last stages of terminal illness’… after that, I just switched off to them.
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… P4: Mm, I've come to terms with… death

For all other patients the care that district nurses initially provided was for none acute physical reasons such as dressings and medication administration:

“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 that’s how come I had the district nurse in.”

It appears that district nurses are most accepted and understood in the home when they are conducting a physical care role, and at best it appears unusual for district nurses to enter into the home for non-physical care reasons. In addition, patients and carers had no choice about other healthcare providers meeting their healthcare needs if they wished to have the care conducted at home.

3.5.2 The right type of illness

Patients and carers perceived access to district nursing as being characterised by a specific set of conditions normally linked to the patients’ physical health (rather than
the service that district nurses could provide). The only factor which was always represented as the district nurses preventing home care occurring was IV therapies.

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 initially making district nursing occur in the home, illness 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. Several patients described episodes of unexpected illness that meant district nursing care was no longer an 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 sometimes reported to be other healthcare professionals such as often GPs and community matrons:

“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 and it appears in some cases that district nurses did not question how medical ideas were being privileged over the desires of their patients to remain at home:
“P19: I'd rather spend my time at home with the family than in hospital with a load of strangers.”

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 (verbal or written) were given to patients or carers regarding what care could be managed at home:

“P17: I think you've to sort of recognise a point where you can be cared for at home and when you can't be… 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 and an emphasis appears to be placed on the patient to recognise and accept this line rather than negotiate and discuss the boundaries of home care with district nurses.
3.5.3 Effect of district nursing on the home

Many patients and carers felt that the district nurses did not affect the home:

“Interviewer: [does] district nurses coming in affect how your home feels?

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 pat the dog and what-have-you when the excitement has died down.”

However, where ‘disruption’ was a concept which was given credence in relation to district nurses and ‘the home’, it was also apparent that any disruption to the home was, for many patients and carers, considered less of a disruption than for the patient going to hospital.

“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.”

In addition there is an emotive and meaningful link with the home which goes beyond nonchalantly ‘choosing’ it as a place of care:

“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?
It can therefore be argued that the home and expanding the possibility for care are not merely a matter of choice, it is vital; vital in the sense that the home is vital to patients and carers identity.

3.5.4 Summary
These data presented above demonstrate how physical illness was (nearly) always the reason for district nursing involvement, but paradoxically, illness could also be the reason for why district nurse could no longer maintain the patient at home. District nurses, far from negatively altering the home actually maintain it and become “vital”. However, the power and knowledge for maintaining the home lie primarily with the district nurses and ideas of medical best practice, not patients and carers desires and needs to remain at home.
Section 4: Discussion

4.1 Introduction

This discussion section critiques the current constructions of quality that circulate in relation to district nursing. To begin the limitations of the study are discussed followed by discussion of the demographic findings. This is followed by the main findings which went across all demographic groups. Finally a detailed discussion of clinical implications is undertaken with reference to some of the most recent policy initiatives.

4.2 Study limitations

There are many limits to this study and a detailed account of these is beneficial to frame the subsequent discussion and understand the conditions that produce this report.

4.2.1 Sample limitations

One of the aims of this study was to explore differences across demographic groups in the construction of quality palliative and supportive care. There were however, limits to the sample. Whilst not aiming for a statistically representative sample patients with a non-cancer diagnosis only made up 23% (n=6) of the sample. This is far from the national average of 70% of patients who died from non-cancer related causes. Entirely absent in this sample were any self-identifying lesbian, gay, bisexual, and transgender (LGBT) couples or individuals, or working class individuals (though some participants had started their life as working class they had become
middle class in terms of income, work and culture later in life). Black and ethnic minorities (BME) were also under-represented with only two participants (P23 first generation Jamaican, and P1 second generation Indian) being from a BME community. These are all factors which are known to affect access to palliative care services.\textsuperscript{60-62} However, without access to the caseload demographics and knowing who was or was not offered an opportunity to be involved in the research it is difficult to assess the reasons for omissions in this research project.

A larger and more purposefully diverse study sample would help explore how different demographics interact 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.

4.2.2 Ethical limitations
The ethical limits that influenced this project were specified and were highly influential in who participated in the study. For example, 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. Therefore, the limits relating to sample recruitment remain largely unaccountable for in the research.

4.3 Demographic factors effects on the quality of district nursing

As discussed in section two, the sample whilst broad, only had two patients who were from a BME group, individuals with a non-cancer diagnosis were under-represented and lacked any self identifying LGBT individuals. It is however, still possible to have some limited discussion around these demographic features.

4.3.1 Black and Minority Ethnic (BME) individuals and district nursing

BME individuals have a lower uptake and awareness of services which is sometimes being linked to previous experiences of prejudice and at other times language barriers. Whilst BME individuals were under-represented in the sample, those who did take part did not have lower awareness of the services that were available to them; instead they had the same low awareness as all the other participants.

Within the broader literature on BME individuals and palliative care there appears to be a greater desire for life sustaining treatment, and patients are less likely to die at home. However, there is no research specifically addressing BME patients’ preferences for where their care occurs. Therefore, it is possible that district nursing may have to be more aware of the increased desire for sustaining life and help
patients and carers negotiate where they would prefer for this care to occur, adapting services as necessary to fit their cultural needs. Further research in this area would be beneficial to develop the quality of district nursing care for BME individuals.

4.3.2 Non-cancer versus cancer patients in relation to district nursing
The literature continues to suggest the historic disparity between cancer patients and non-cancer patients’ quality of palliative and supportive care still exists.\textsuperscript{64-65} Whilst acknowledging their under-representation in the sample, this study did not find any differences in patients’ and carers’ constructions of quality in relation to their district nursing provision.

4.3.3 LGBT individuals and district nursing
The complete lack of representation of any self identifying LGBT individuals in the sample is in itself problematic. The literature on palliative care and LGBT people suggests that there is a lower uptake of services due to a fear of discrimination\textsuperscript{66-67} but also a high degree of advanced care planning\textsuperscript{68} because of fear of prejudice in long-term care settings, there is a strong preference for home care.\textsuperscript{69} In addition there is a stronger preference for palliative care over life prolonging treatments.\textsuperscript{70} Therefore, the absence of a demographic group which the literature suggests have strong preferences for palliative care at home, but were completely unrepresented in this study suggests the need for a more focussed research programme in this field.
4.4 Summary of the study’s main findings

It is clear that there were many elements of district nursing care which enhanced the quality of care that patients and carers experienced, such as developing a friendship with patients, offering psychological support, and providing nursing care that ensured patients remained at home. These elements of district nursing care have previously been highlighted in the literature as contributing to quality of care,\textsuperscript{12, 14, 57, 71} how it has also been questioned how ubiquitous elements such as psychological support are when district nursing practice is observed.\textsuperscript{22} Whilst it has been argued much of what contributes to the quality of district nursing is ‘invisible’\textsuperscript{21} and cannot easily be represented what has not been examined is what prevents quality care occurring. This study suggests that two key elements prevent quality occurring, namely: district nurses being busy and/or being perceived as busy; and patients and carers lacking knowledge of district nursing service. Busyness prevented quality care occurring by precluding patients and carers from approaching district nurses for additional and/or alternative care which was commonly available. Because patients and carers did not attempt to find the boundaries to district nursing care they were left with the impression that district nurses would ‘do anything’ and this was sublimated into being representative of quality. Similarly a lack of knowledge may have prevented patients and carers accessing services. Whilst it is unreasonable to suggest that patients and carers should have detailed knowledge of district nursing services, the empirical data suggests that there is a systematic lack in the ways that knowledge of district nursing services are distributed; patients and carers predominantly only had knowledge of the care that they were currently receiving from district nurses and there were no materials or processes in place to ensure that patients and carers gained knowledge of the types of care that district nurses commonly report providing.
In addition this report also considers ‘the home’. In previous research district nursing care has been represented as having an intrinsically negative/unethical effect by disrupting the home.\textsuperscript{72-73} However, the empirical data suggests that this is not the case and that district nurses become an important factor in maintaining the home as a site for patients and carers to maintain their personhood and hence is representative of quality care. However, there were also examples where district nurses failed to maintain the home in ways that respected patients and carers priorities, such as remaining with their family, by not conducting Intravenous (IV) medication administration and other forms of care. Whilst it is recognised that some district nurses teams offer IV therapy management at home, where they do not it could be argued that the district nursing service is not offering (or facilitating) quality care.

These findings challenge the views of quality care as being something which is (at least in part) commensurate with efficiency. They also support some aspects of the Francis Report\textsuperscript{28} which argues quality of care was at times entirely absent because of a focus on financial targets and efficiency. However, this report does not support the implications of the Francis Report that measuring should focus on patient reported outcome measures. Instead, it concludes that it is measurement itself which is one of the key problems in developing and delivering quality care. Instead, this report suggests quality needs to be considered in terms of ethical theories, in particular the ideas put forward by Gallagher\textsuperscript{74-75} of ‘slow ethics’ which Nagington\textsuperscript{2} suggests would allows nurses more time to develop care in novel ways in accordance with patients’ and carers’ their desires.
4.5 Busyness and its impact on the quality of care

As discussed, busyness has negative effects on patients and carers ability to understand and develop their district nursing care. This discussion focuses first on what produces busyness and secondly what may be done to reduce it.

4.5.1 Will competition increase busyness?

Competition in the form of an internal market is now well established and expanding within the NHS. It has been argued that the way that competition encourages the production of more for less contributes to the production of busyness in everyday life.\textsuperscript{76} The effects of busyness have been documented in multiple areas such as domestic life,\textsuperscript{77} work life,\textsuperscript{78} and political activism\textsuperscript{79} but not in healthcare. Whilst opposing concepts like ‘wastefulness’, ‘inefficiency’ and ‘slowness’ appear undesirable qualities, they remain subjective and require further analysis. For example, efficiency in district nursing becomes contested when tasks such as lighting fires and cleaning are done\textsuperscript{80} yet remains uncontested when dressing leg ulcers. By this logic, efficiency pertains to the tasks which only a district nurse can carry out, meaning it is inefficient for district nurses to spend time talking in the style of a friend. Whilst it is clear that not all nurses abide by the restrictions placed on their practice,\textsuperscript{80} efficiency in modern day society is so pervasive and considered necessary\textsuperscript{81} that to be considered inefficient risks being untenable in one’s role. Therefore, ‘efficiency’ begins to prevent a variety of actions which may not have measurable benefits for patients. With the increasing marketisation of district nursing it is likely that the problems associated with the production of busyness in district nursing care will become increasingly relevant to clinical practice. The effects that private health care companies will have on the quality of district nursing care are
unknown, but this report strongly suggests that furthering a target driven culture of efficiency in district nursing will not improve the quality of care from patients’ and carers’ perspectives.

4.5.2 District nursing workloads and quality of care

Workload data on district nursing has not been routinely and nationally collected since 2003. There is evidence from district nursing perspectives that workloads have increased over this time, and anecdotal evidence from Wales suggests some workloads have increased by 20-25% from 2011 to 2012. Whilst rigorous figures are unknown nationwide several factors suggest that an increase in district nursing workloads may be occurring:

- An increased focus on providing care at home
- A decrease in the number of district nurses
- District nursing services are unable to refuse referrals (unlike hospitals who only have a finite number of beds)

It is likely that increased workloads also contribute to the busyness that patients and carers report.

4.5.3 Can choice drive quality?

In terms of policy, can choice increase the quality of care? Key to answering this question is how choice is instigated. For individuals who experience poor care, being able to choose an alternative provider may produce better quality care for that individual. Putting aside arguments about whether patients and carers can exercise choice, discussion instead focuses on how choice acts to produce or preclude quality.
If choice is to function in a market to produce quality, measures of quality must be produced to allow choices to be made.\textsuperscript{86} Examining the various tools that have been developed to measure district nursing care there is little to object to in what they regard to be quality care such as pain control and preventing social isolation. However, it is this effort to account more fully for time and money by measuring quality in standardised ways to compare services which becomes problematic:

\begin{quote}
“\textit{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.”} \textsuperscript{87: 665 - 667}
\end{quote}

Standardised performance measures produce a market economy where measures must exist for choices to be made (this applies even if patients and carers do not use the measures to make their choices\textsuperscript{43, 88} because measures must still be produced for the claim to be made that choice does exist). The question therefore becomes: in what ways does choice, through the production of measures effect the quality of care?

Choice within neoliberal healthcare markets, whilst liberating the individual from poor care, systematically aims to increase efficiency. This increasing efficiency has the
effect of producing a social acceleration, bringing with it busyness such as described by the patients and carers in this study. Therefore, choice appears not to produce quality for a whole system (though it may for the individual) but instead produces systems of measurement which restrict the care patients and carers may access. Hence it restricts district nurses’ abilities to develop a caring relationship referred to by some patients as ‘friendships’ with patients who do not have legitimate physical care needs. In a similar way patients who had lay carers to undertake care often received much less district nursing support than those who where on their own. Patients and carers rarely reported exercising choice over the number of visits and level of support that they could access from the district nurses. Therefore, if quality is to be produced it does not appear it can be achieved in district nursing via the mechanism of ‘choice’. Therefore, this report rejects measuring, choice and any other way of attempting to direct practice so that it can be measured. This is not to say that guidelines such as those for pain 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 as suggested be used to measure quality of care\textsuperscript{30} as it will begin to restrict what care can become by diverting care in a healthcare market in particular ways so that quality can be measured and demonstrated.

4.5.4 How can policy reduce busyness?

What then is the solution to reduce busyness within healthcare and increase quality of care? Busyness will undoubtedly remain since eliminating it is implausible, it has always been and always will be possible for unexpected events to occur which put strain on a service resulting in busyness. However, if ‘measuring’ and ‘choosing’ as
underpinning philosophies are removed then busyness may cease to be a structuring condition of district nursing.

In relation to district nursing workloads the empirical data gathered in this report did not directly assess district nursing workloads. Therefore, no direct link can be made between perceived busyness and increased workloads. However, it is important that policies which aim to reduce or re-organise district nurses to create more efficient systems of care take into account how any increased suggestion that district nurses are busy negatively impacts on patients and carers perspectives on the quality of district nursing care.

In relation to how district nurses should instigate clinical guidelines and research the concept of ‘best practice’ may continue, but measures should not be created to ensure quality of care is occurring. This is something which current UK policy aims to remedy by promising to end relentless measuring of processes and instead focus on clinical outcomes. However, policy fails to realise that choice and competition requires the production of measurements so that informed choices can be made, and that measuring may preclude quality care regardless of what is measured. In addition policies such as the recently published Care in local communities: a new vision and model for district nursing which call for ‘maximising efficiency’ need to develop a critical understanding of the negative effects that this has on the ethical quality of care. As demonstrated measuring (which is a logical necessity to maximising efficiency) is key to the production of a busy work environment which prevents patients making their needs and wishes known. Therefore, if the ‘holistic care’ district nurses argue they provide is to be recognised by patients as such, there is a need to
reduce and possibly eliminate measurement in district nursing and there needs to be an avoidance on focussing on maximising efficiency. This will reduce busyness and enable patients and carers to feel more able to explore their care needs with district nurses without increasing healthcare costs through additional staffing.

4.5.5 Can measurement remain?
Some measures such as mortality rates may need to remain to ensure safety and public accountability. However, where a decision is made to measure it is equally important to consider the possible negative effects of measuring alongside any positive ones. Healthcare policy in relation to district nurses is therefore encouraged to move away from a neoliberal market based service, to one which focuses on the immeasurable ethical ways in which humans interact.

4.6 Knowledge and its impact on the quality of care
If knowledge is developed for patients and carers, it is equally important to consider how the knowledge may be acted upon, and what ways it would be most appropriate to facilitate this for patients and carers with palliative and supportive care needs.

4.6.1 Knowledge to produce developments in care
Within healthcare there have been many examples of patients taking control of their care to develop it in ways which they, the patients, desire rather than just accepting the direction of the healthcare professionals. For example, the independent living movement for people with disabilities. However, patients and carers with palliative and supportive care needs face two key problems in attempting to develop their care in the radical ways which occurred in the 70s and 80s with the independent living
movement. Firstly, patients with palliative and supportive care needs may only have a very limited time left to live. Whilst it is not unthinkable for an individual patient to take over their care, the time taken to establish the frameworks of independent financial arrangements and a team of people to conduct care takes weeks and months, by which time many patients will have died. Secondly, as discussed in section 4, the home becomes reliant on district nurses, and the home is “vital” to patients and carers. Therefore, any radical action with puts district nurses into question has a risk of putting the home and the patients and carers themselves at risk of being able to function in an acceptable way. Whilst as theoretically distasteful as some authors find more piecemeal ways of developing social life\textsuperscript{91} in the case of palliative and supportive home care provided by district nurses, this seems the only option which can reliably be explored without significantly risking harm to patients and carers.

4.6.2 Networking to facilitate knowledge distribution

Networking is one way in which patients and carers may act in a non-radical way but still develop knowledge of their care and hence gain power to develop it. However the empirical data suggests that networking is problematic for the majority of patients and carers who receive district nursing care at home. Whilst some patients were in contact with hospice day care services, only two patients (P12 and P26) discussed their district nursing care with other patients, and for P12 this was only prompted by the research process. This suggests that networking and discussion of district nursing services does not occur in the normal interactions of patients. Therefore, the practicality of face-to-face networking is questionable however, physical interaction is no longer the only way that networking occurs. In a world that is becoming
increasingly connected via the internet networking is now occurring without individuals ever having met face-to-face.\textsuperscript{92-93} Even within healthcare, patients and carers are able to, in a limited way, collectively influence each other's choices through official sites such as NHS choices.\textsuperscript{83} 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, even the basic commentary allowed for hospital and GP services is disallowed. Empirical evidence for suggesting such virtual forms of resistance are limited in this study but other research is beginning to explore how social media sites such as facebook are beginning to play a role in patients and carers informally exchanging information on hospital based services.\textsuperscript{94} There is no evidence yet that any similar actions are taking place in relation to district nursing care but this does demonstrate in principle that social media can and does play a role in connecting patients and carers.

4.7 The home and its impact on the quality of care

The value of the home as a place of care has previously been highlighted in economic terms as being cheaper and more efficient,\textsuperscript{95} and also decreasing the incidence of negative outcomes such as infections.\textsuperscript{96} Whilst the non-economic, more emotional value of home care is something claimed in district nursing literature\textsuperscript{84} it has previously lacked an empirical basis. This study has given empirical standing to the emotional value of district nurses maintaining the home in relation to how it
maintains patients and carers identities. In addition this study challenges that ‘the home’ is a space which is negatively affected by nurses. Instead because of the approach to data analysis, the home was assumed as constantly being maintained by a variety of discourses. Therefore, district nurses merely add to what is used to claim the home is a home by providing the means for patients and carers to remain there when physical illness may prevent it otherwise being so. Therefore, district nurses cannot be considered to be disruptive to ‘the home’ as suggested by other researchers in any way that any other factor is. Instead, disruption to the home should be considered when district nursing cannot be utilised to maintain the home in a way which patients and carers find acceptable. Several examples were given in the data of the need to go to hospital for a variety of interventions, IV infusions being one of the primary reasons given. In several cases this was not what patients would have ideally wished for, but expressing this to district nurses was problematic. Therefore, further consideration needs to be given to a more flexible approach to the management of patients and carers at home. It may be that in some cases that optimal medical management in accordance with current medical research cannot be given at home. This in itself is not indicative of poor quality, logically there are certain scans and interventions which can only be conducted within a hospital environment because the technology required is too large and/or expensive to reproduce in individual homes. However, in some cases, it was clear that alternatives to hospital care were not explored between patients and district nurses, and instead, hospital care was the inevitable outcome of what medical best practice dictated rather than an informed discussion of how care could be continued at home, even if care would be different. Again, the ways in which district nurses appeared ‘busy’ and the way in which patients and carers lacked knowledge about district nursing services can be
implicated in exacerbating the reported lack of conversations about how the home environment could have been maintained.

4.8 Clinical implications

There are several clinical implications that this research project has in relation to clinical practice which are discussed below. In addition the research findings are discussed in relation to one of the key current policy drivers in district nursing care, the 6Cs: care compassion, competence, communication, courage and commitment.

4.8.1 Early support visits

There is a body of evidence in the literature that district nurses provide early support visits which are characterised by psychological and social support prior to patients needing more ‘hands on’ palliative care. However, in this research project there was little evidence of these visits occurring prior to the development of physical care needs. Why this is the case is unclear, but this research suggests that measuring and driving for efficiency is one key reason. Instead, district nurses, in all but one case (P4) initially met with patients for physical reasons such as dressings or medication administration. Therefore, it would appear that patients without physical care needs stand a low chance of coming into contact with district nurses. Whilst some patients did receive support visits after their physical care needs ceased, again it appears from the participants’ perspectives that district nurses directed the occurrence and nature of these meetings, not patients or carers. Therefore, whilst this report’s findings support the notion of support visits, it tentatively suggests patients and carers need to be given more knowledge and opportunities to develop the visits in ways that would benefit them. Further research into this area would be
particularly beneficial. Policy documents appear to be silent on the issue of support visits, therefore developing policies which allow or encourage early support visits may be beneficial.

4.8.2 What is district nursing? The patient and carer perspective

It is clear throughout this report that patients and carers do not understand the district nurse in the way that district nurses see themselves as ‘holistic’ carers. Patients and carers predominately view district nurses as concerned with physical care tasks pertaining to the patient and this is only altered when district nurses act differently which some district nurses did. The actions of district nurses, whilst sometimes timely, were not always so, and left patients who were in regular contact with a healthcare professional with unmet needs because they remained naive of what district nurses could do. There is a clear need for individual district nurses to be allocated enough time to explain service provision to patients and carers. In addition service managers should develop ways and means to proactively distribute information about district nursing services for patients and carers with palliative and supportive care needs. This may include but is not limited to information leaflets and exploring the use of information technology. Whilst the use of technology has been recognised in recent policy documents as improving the quality of disease management at home, its role in improving the quality of district nursing care remains relatively unconsidered. This report suggests that there is particular role in social media for patients to exchange information on the services that they receive in their home so that they can request novel services from their district nurses.
4.8.3 District nurses’ interactions with the patient

There is a need for district nurses to begin to, and allow interaction with, patients and carers in ways that go beyond physical care discourses. District nursing care, whilst rightly concerned with physical care tasks must also (where possible) develop patients’ and carers’ understanding of how district nurses can support their current and future care needs. The knowledge for this remains largely with district nurses and leaves a moral responsibility on district nurses to share and develop this knowledge with patients and carers. Whilst written information can go some way there should be a managerial understanding for the need for time and resources to be used in open-ended interactions in order to allow quality care to occur.

4.8.4 District Nurses’ 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. Similar conclusions have been made in observational research where carers needs were seen as tangential to district nursing practice.²⁴ However, it was demonstrated in the empirical data that when district nurses did address the carer (even for brief interactions) it was appreciated and allowed dialogue to open up. This suggests that the support needs which district nurses are required to fulfil may not be extensive and that it is more about opening a dialogue rather than providing large amounts of psychological support to carers. Healthcare policy in this area remains particularly weak. Whilst policies⁹⁹, acts of parliament¹⁰⁰ and a substantial body of research literature investigating carer needs in palliative and supportive care have been developed.¹³-¹⁴, ¹⁶, ¹⁰¹-¹⁰⁹ Recent initiatives and policies on improving district nursing care are entirely silent on the broader
needs of carers beyond training them to provide care for patients.\textsuperscript{7-8} Therefore, without broader policy reflecting the ‘carer specific’ needs highlighted in policy, law and research it may be difficult for district nurses, patients and carers to alter their caring relationship to focus on carers needs.

4.8.5 District nursing for patients with no significant lay carer
The research literature on home palliative care does not address the needs of patients who are largely on their own. The results of this study suggest that further consideration needs to be given to the support needs of patients who have no ‘significant lay carer’ i.e. a spouse, child or close friend who visit regularly. It was clear that district nurses making brief visits which were not made to carry out physical care were important and highly valued. Because of the low numbers of patients who lacked any full time lay carer (n=2, one of whom had daily district nursing visits for pain relief patches to be changed) in this study it is difficult to assess what other aspects to district nursing care are valued to this patient group.

4.8.6 Measuring the quality of district nursing
Measurement and further market based reforms that would necessitate measurement in district nursing need to be reconsidered. It is the argument of this report that measurement does not produce quality, and may often produce a culture of busyness which results in an unethical form of care occurring. Therefore, any measurements which do remain in district nursing must also be considered for the potential for a negative, as well as positive effect on care.
4.8.7 The 6Cs

The recently published *Compassion in Practice: Nursing Midwifery and Care Staff* *Our Vision and Strategy* puts forward the ‘6Cs’ as a way to address the crisis in providing compassionate care which is suggested as a recent problem highlighted by the poor standards of care in *The Francis Report*. However, it is important to highlight that the crisis of compassionate care was being considered on a moral level before any of these recent problems being raised. Therefore, it seems appropriate to critique the 6Cs in light of the above research findings which were themselves derived from a methodology focussed on examining quality of care from a moral/ethical perspective.

*Care*

Whilst consistently providing the right care for patients throughout every stage of their life must clearly be appropriate, it is important to address what frames the ideas of ‘right care’. For instance it is not clear what ‘right care’ is or who determines it. The findings of this research suggest that ‘right care’ is almost always considered to be physical in nature and because patients lack any knowledge of district nursing beyond physical care there is little opportunity for them to reframe what ‘right care’ may mean for themselves. Therefore there needs to be opportunities for patients to explore the concept of district nursing care.

*Compassion*

The 6Cs document suggests the way in which nurses relate to the home is highlighted as key to providing compassionate care. This report supports this assertion and develops it by suggesting that it is important for district nursing
teams to consider which interventions in the home may be offered as an alternative to hospital care such as IV fluids and antibiotics. These considerations should not be entirely framed by consideration of what is medically best. Instead compassionate nursing can be understood to recognise the value of the home and facilitating discussions about home care options based on the value that patients and carers place on being at home. However, whilst this report supports the assertion for district nurses to “encourage patients to be active participants in care and decision making”\textsuperscript{8}: pg 29 it is important for district nurses to recognise how they may curtail the possibility for such conversations to be instigated by patients and carers by appearing ‘busy’ and not providing adequate knowledge of potential service provision.

\textit{Competence}

Competence is suggested to be “the ability to understand an individual’s health and social needs”.\textsuperscript{8}: pg 13 However, what is meant by “ability” and “need” are not clear. For example, is ability being conceptualised (as it often is) in terms of a training need,\textsuperscript{22, 111-112} or can ability to be competent be considered as a result of the prevailing cultural/political organisation of healthcare. This report suggests that whilst considering ability in terms of individual training, there is also a need to consider an organisation’s ability to understand health and social needs. This is tied to the way in which understanding is created. For example, understanding patients and carers health care needs are often considered something which district nurses are responsible for assessing with little thought to how what frames the assessments of these needs. It was apparent that patients and carers viewed district nurses as primarily concerned with the physical care needs of the patient. Where care
expanded beyond these discourses it was of particular value, however, it was always the district nurse who facilitated this expansion. Therefore, whilst competent care is desirable (simply because it is a priori to say that incompetent care is not desirable), it is necessary to understand what frames care as competent. Therefore, it appears that care is currently considered competent when it is primarily characterised by a professional conceptualising patients’ needs in medical frameworks. However, this report suggests that in order to improve the quality of care it is important to allow other frameworks to define what competent care is. For example the act of befriending a patient may help redefine patient’s needs towards a need for social interaction. Competency may therefore be considered more about an ability to allow patients needs to be expressed within the organisations culture.

Communication

Within the 6Cs is it stated that “communication is as important as what we say and do”. Again, this report can support this statement, but it is important to recognise that the analysis of the empirical data presented above demonstrates that “what we say and do” very often frames what communication can occur. Therefore, a nurse who enters a patient’s home and states that he/she has been busy closes down many possible ways for a patient to communicate. Conversely, a nurse who spends time communicating about their/and or the patients social life enables other forms of conversation to take place which facilitates alternative forms of care. Therefore, nurses need to be aware of how they may be closing down opportunities for communication as much as they may be opening them up.


Courage

Specifically in relation to home care, it has been observed in the data that patients and carers can be relatively isolated in terms of the knowledge that they have about district nursing. Therefore, whilst encouraging staff to have “courage… to do the right thing… [and] to speak up when [they] have concerns… [and to] innovate and embrace new ways of working” are all laudable aims, it fails to address how patients and carers (the other half of any healthcare interaction) may be facilitated to have the knowledge to develop healthcare and understand when care falls below accepted standards. For example, patients were often unaware that psychological support was within the remit of district nurses. However, this was never raised as a problem by patients because patients and carers lacked any knowledge that psychological support was within district nurses remits. Therefore, it is suggested that the argument that the concept of ‘courage’ also need to encompass empowering patients and carers with knowledge about district nursing so they can develop services and raise concerns.

Commitment

In relation to district nursing ‘commitment’ has been suggested to include empowering patients to maximise their own health and control their own care. However, within the 6Cs there is no discussion on how this may occur from a patient’s perspective; there is however discussion on how nurses should influence care. Therefore, it is the suggestion of this document that there needs to be further consideration in policy of how to regularly patients in their care. On a practical level there need to be accessible ways for all patients to comment on and share experiences of their care. With remote healthcare using computer technology to
manage patients with chronic conditions at home\textsuperscript{98} it becomes more appropriate for the dialogue with healthcare services to also have computer based options.

4.8.8 Summary

In summary the recent policies which have been put forward to help address poor quality care such as that observed in Mid Staffordshire NHS Trust tend to focus on the ‘front line’, i.e. district nurses. This report suggests that whilst individuals bear responsibility for some of the most severe cases of neglect and abuse, there is also a responsibility on the ways in which organisations are managed that have a substantial bearing on the quality of care that can be given. In particular it is suggested that increasing workloads, aiming for maximum efficiency and constantly measuring productivity must be avoided if district nurses are to be allowed to work in a culture that is capable of placing patient’s priorities above institutional measures and National targets.

In addition, all policies regarding quality of care need to begin to integrate carers in ways that go beyond viewing them as instruments to give care, and instead understand carers as people worthy of care and support themselves.

4.9 Future Research

Increasing patients’ and carers’ knowledge on district nursing and community palliative care services in general is necessary. Whether such lack of knowledge is occurring because of an active or passive avoidance of district nurses discussing service provision is unclear. Further ethnographic work may help understand how any why there is a lack of discussion on such topics.
Disseminating knowledge via information leaflets is backed up by previous studies and the empirical data on this study. However, it is not yet possible to clearly delimit what information should be included. Further research is needed to establish the style, content and format. It is strongly suggested that it be patient and carer led.

Other means of distributing information should also be explored for their utility in this patient/carer group such as: online forums, social media, and expanding current systems such as NHS choices.

The way in which district nurses interact with carers remains unclear and does not clearly match the rhetoric of government policy. Further research is necessary to establish what other barriers (in addition to a lack of knowledge and busyness highlighted in this report) prevent carers needs being assessed by district nurses.

The effect of increasing district nursing workloads on the quality of care from patients’ and carers’ perspectives remains unknown. Whilst it may be a logical conclusion that increasing workloads increases busyness and hence decreases the quality of care, this research did not assess district nursing workloads and so cannot make these conclusions. Therefore, further research is needed to assess the relationship between workloads and the quality of district nursing care.

Finally, more in-depth research which specifically addresses the needs of demographic minorities such as LGBT, BME individuals and those who have no full-
time lay carer would be beneficial to understand how district nursing services can better be adapted to these under-represented groups in this research study.
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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 Naginton
PhD Student
The School of Nursing, Midwifery and Social Work
University of Manchester
University Place
Oxford Road
Manchester
M13 9LP mail: Maurice.Naginton@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 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.

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.
Appendix 2: Information sheet for carers

If you are interested please continue to read this in full. Would you involve for your family or friends? Would you also like to take part? Would you like to take part in a research study investigating the views of patients with severe palliative and supportive care from district nurses? Patients' and carers' views on what is quality about the palliative and supportive care provided will be used in future research projects.

If you have a concern about any aspect of the study, please ask to speak to the researchers who will do...
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 3: 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 .........
Appendix 4: Initial interview protocol

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 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 effect quality of care?
If different nurses, do they know them? How does this effect quality of care?

**Closing questions**
Anything else patients want to discuss?
Any questions for me?

Thank for participation
Appendix 5: Final interview protocol

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's?
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 DNs
Had you heard of DNs 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?
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?

**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 6: Summary of core and auxiliary themes

<table>
<thead>
<tr>
<th>Core Themes</th>
<th>Auxiliary Themes</th>
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<tr>
<td>Busyness</td>
<td>Time and Timekeeping</td>
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<td>Knowledge</td>
<td>Future care</td>
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<td>Psychosocial care and chatting</td>
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<td>Affective economy of DNing - becoming young</td>
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<td>Previous DN experience</td>
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<td>Patient performative concepts</td>
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<td>Genesis of district nursing care</td>
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<td>Information leaflet</td>
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### Appendix 7 – Demographic details

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