District nurses role in palliative care provision: a realist review

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Abstract

Objectives: The aim of this review is to construct a detailed account of the role of the district nurse (generalist registered nurse providing nursing care in primarily home settings) in providing palliative care, to determine if and how district nursing care provides effective care to such patients at home, and to examine the utility of a realist review for the above purpose..

Design: Realist review of literature.

Data sources: Papers in English reporting aspects of the district nurse role in the provision of palliative care are included. Electronic databases (Ovid Medline, Cinnahl, British Nursing Index, Embase, PsycINFO and EBM reviews) were searched, supplemented by citation tracking and grey literature searches.

Review methods: Assumptions about district nursing practice with palliative care patients are derived from a range of sources. Reviewed papers are interrogated to support, refute or develop these statements.

Results: Forty six papers employing a range of research methods are incorporated into the review. Studies focus on district nurses, patients, family carers and other professionals and include work from a range of countries. Studies highlight the value district nurses place on palliative care provision, the importance of developing a relationship with patients, and the emotional

difficulties of providing such care. District nurses have key skills in providing physical care and in coordinating the work of others, but struggle more with psychological aspects of care. District nurses report feeling undervalued, and express some reluctance to work with other health and social care professionals to provide care.

Conclusions: There is little in this synthesis to shed light on the outcomes of care or to explicitly guide practice. District nurses clearly articulate what they consider to be important, but research in this area is limited and needs to undergo a renaissance to examine what is important: namely what district nurses do in practice; what patients and family carers views are on what they do and do not do; and how district nurses can improve care outcomes. The inclusiveness of realist review works well for this field of study.

What is already known about this topic

- District nurses are essential to the provision of community palliative care services, but there is little written on how they enact their professional or clinical role with these patients.
- Palliative care is considered by many district nurses to be their preferred and most rewarding area of practice.

What this paper adds

- There is little research that can guide improvements in district nurse palliative care practice.

- Highlights the need for future research to focus on a number of areas: outcomes focused work; work observing real life district nurse practice; and work examining the views of patients and family carers about processes and outcomes of care.
- A realist review approach has utility in guiding reviews of nursing practice.

Keywords

Community health nursing; home care services; palliative care; review

Introduction

Providing nursing care to people in their own communities and domestic home settings is central to health policy in many countries (Department of Health, 2000; Royal District Nursing Service, 2009; Department of Health, 2001). Some registered nurses providing such care specialise in caring for those in particular situations or with certain diseases (i.e. palliative care, respiratory care), others, whilst specialists in providing community care, care for those with a range of health needs. The terms in use to describe such nurses vary (i.e. district nurse, community health nurse, home healthcare nurse), as do exact job descriptions, but most have a core role providing skilled nursing care in a domestic home setting to patients with a wide range of health and nursing needs (see box 1 for details). The term 'district nurse' is used broadly here to describe this type of generalist care, whatever the title of the nurse providing care.

< insert box 1 around here >

Definitions and descriptions of district nursing practice frequently highlight a number of common elements: the style of care; the recipients of care namely individuals and the wider community; the location of care at home or in the community; and a role in assessment, care coordination and referral to others (CPHVA, 2003; District Nursing Association, 1989; Royal College of Nursing, 1990; Community Health Nurses Association of Canada, 2008; National Organisation of District Nurses (Riksföreningen för distriktsköterskor), 2008).

However, such definitions do not describe exactly what nursing services a district nurse provides, how they enact their role, and what the outcomes of such care may be. This poor understanding of what exactly district nurses do is compounded because they frequently work in home settings where their work is invisible and unobserved (Hallett and Pateman, 2000;McIntosh, 2000), such that they can even be unaware of the working patterns of district nurse colleagues (Walshe *et al.*, 2008). It is argued that this 'invisibility' of home nursing care is compounded because district nurses work with a range of client groups, often those who have poorly defined forms of ill health, where outcomes are hard to identify, and with little external acknowledgement of their skills and knowledge base (Goodman *et al.*, 2003).

It is important to understand exactly what district nurses do in providing nursing care in home type settings in order to ensure that the care they give is appropriate, of the highest quality and maximises care outcomes. One critical area which could be explored as an exemplar of district nursing practice is palliative care. District nurses frequently identify palliative care as part of their role (National Organisation of District Nurses (Riksföreningen för distriktssköterskor), 2008;Community Health Nurses Association of Canada, 2008), and as an exemplar of the best care they can offer (Griffiths, 1997). District nurses often provide a major element of the home care for those in the palliative phase of illness (Audit Commission, 1999;Beaver *et al.*, 2000). This

reflects a general shift in emphasis to primary care, including primary palliative care (Murray *et al.*, 2004), and recognition that moving palliative care from acute to community sectors could provide cost savings (Hatziaandreu *et al.*, 2008).

Understanding what and how district nurses contribute to such primary palliative care is important in terms of patient care and workforce policy direction. We need to know how district nurses work with such patients, whether and how their work is affected by contextual and policy related issues, and how their work affects the outcomes of care. Valued outcomes of primary palliative care are wide and include issues such as symptom control, satisfaction with care, quality of death and dying, and place of care and death (Mularski *et al.*, 2007; Pasman *et al.*, 2009; Steinhauser, 2005; Teno, 2005).

An earlier review by Bergen (1991) examines what (and how effective) the role of the district nurse is in caring for terminally ill people. Bergen (1991) concludes that the nature of the district nurse role is well established, with strengths in providing practical nursing and co-ordinating care but areas for development in providing psychological support. She identifies an issue of weak theoretical underpinnings to the research reviewed, and comments on its second hand nature, because it is seen through the eyes of professionals rather than patients. The review reported here builds on this to examine more recent literature exploring how district nurses provide nursing care to patients in the palliative phase of their illness.

The Review

Aim/s

The primary aim of this review is to examine how district nurses provide nursing care to patients in the palliative phase of their illness. We examine why such patients are cared for by district nurses, whether the home context influences the nursing care provided, and the outcomes of care. A further aim is to examine the utility of realist review methods in this context.

Review design

There are different approaches to synthesising research. Each has strengths and weaknesses, and a relatedness to either qualitative, quantitative or both forms of evidence (Dixon-Woods *et al.*, 2005; Boaz *et al.*, 2006). One approach which has merit in incorporating different types of evidence, and in exploring how complex interventions work is realist synthesis (Pawson, 2002; Pawson *et al.*, 2005; Pawson, 2006). Realist reviews have an explanatory rather than an evaluative focus, and aim to uncover the mechanisms of how complex programmes work, with particular reference to contexts and settings. The overall intention is to create a model of how, whether and why something works, which can then be used to provide advice on implementing or changing the intervention (Pawson, 2006).

Many of the features of district nursing practice appear to match the aspects that Pawson (2006) suggests suit this type of review: the intervention requires the active input of individuals; their role is influenced by outside influences such as policy and patients; they are embedded in multiple social systems; and they borrow interventions from other services. A realist review method has seldom been used in nursing and is employed for this review, and evaluated as to its utility in this setting.

The essential steps in a realist review are clarifying the scope of the review, articulating the relevant underlying theories, searching for evidence, appraising and synthesising the evidence.

Clarify scope

Clarifying the scope involves identifying the review question and refining the purpose of the review (Pawson *et al.*, 2005). One purpose of a realist review is to 'review official expectations against actual practice'; examining in this case the way that district nursing is practised against the theoretical and policy expectations of such nursing care.

This review is concerned with the nature of district nursing practice with patients in the palliative phase of their illness. We are interested in why such patients are cared for by district nurses, whether the home context influences the nursing

care given, what care district nurses give, and whether the nursing care given by district nurses influences patient outcomes. The scope of the review is international, examining the work of all 'generalist' nurses who provide nursing care in community or domestic home settings to patients in the palliative phase of their illness. The scope is 'generalist' in that it does not examine the work of nurses who specialise in the provision of palliative care, but those who provide such nursing care alongside caring for patients with a range of other conditions.

Articulate key theories to be explored

A defining feature of realist reviews is the identification of the theoretical drivers for the intervention or programme under review, which are then interrogated using the evidence from the review. Such drivers are the expectations and rationales for why the intervention might work. It is suggested that such ideas may be found from a number of sources such as policy documents and research literature (Pawson, 2006).

To facilitate identification of theoretical drivers to district nursing palliative care practice, an initial, exploratory literature search was undertaken, incorporating international research literature, core district nurse textbooks (Burley *et al.*, 1997; Sines *et al.*, 2001; Spencer *et al.*, 2001; Hyde, 2001; Bryar and Griffiths, 2003; Blackie, 1998; Turton and Orr, 1993; Malin *et al.*, 1999; Baly *et al.*, 1987; Watkins *et al.*, 2003; Lawton *et al.*, 2000), and UK policy documents

(Department of Health, 2003b;Department of Health, 2005c;Department of Health, 2003a;Department of Health, 2002;Department of Health, 1996;Department of Health, 1997;Department of Health, 2006;Department of Health, 2001;Department of Health, 2005b;Department of Health, 1999).

Few texts identify an explicit theoretical underpinning to district nursing practice. Only one text book (Lawton *et al.*, 2000) identifies an explicit framework around which its exposition of district nursing is based, using Davies and Oberle's (1990) research on the supportive role of the nurse. As a framework developed to explore palliative care this has utility in this review, although it is rarely referenced in other district nursing literature. It is used to guide a related review (Widger *et al.*, 2009). Whilst models and theories have been developed or discussed for home nursing e.g. (Albrecht, 1990;Kratz, 1976;Falk Rafael, 2000;McGarry, 2003;Dixon, 1999;Coombs, 1984;Byrd, 1995), there is little evidence that these models or theories are used in practice. Some papers identify theoretical constructs to explain some aspects of the district nurse role (for example the awareness contexts of Glaser and Strauss (Luker *et al.*, 2000)), but none have an overarching theoretical framework to guide all aspects of practice. It is argued that nurses find it difficult to accurately and comprehensively explain what it is that they do and know, and why their discrete knowledge base and practices are significant for those in their care (McKenzie *et al.*, 2007), and this may be why explicit theories are rarely used to guide practice.

However, whilst explicit theories of district nursing practice in palliative care do not appear to overtly drive district nursing practice, it is likely that there are implicit assumptions (often called 'theories of change') about the approach, and why it achieves its stated aims and objectives. Pawson (2006) suggests that implicit theories about practice are often to be found in the introduction and discussion sections of research papers, and also in administrative, legislative and planning documentation. A key initial stage in this review is therefore identifying such implicit assumptions and theories in the sources discussed above, and the empirical studies identified in the formal search strategies discussed below. In this way the implicit assumptions which appear important to district nursing practice with palliative care patients are continuously iteratively identified, initially based on statements drawn from the framework of Davies and Oberle (1990). These are summarised as eight statements about district nursing practice with palliative care patients in box 2.

<Insert box 2 around here>

Search methods

A number of methods are used as part of a comprehensive search strategy. First, a number of electronic databases were searched. A start date of 1990 was set for the searches, as the date from which UK legislation which affected the role of the district nurse was enacted, and to build on the prior review which

incorporated literature up to 1990 (Bergen, 1991). Databases searched (in 2009) include Ovid Medline, Cinahl, British Nursing Index, Embase, PsycINFO, and EBM reviews. Each search was constructed differently to use the relevant search terms or MESH/Thesaurus/Keyword headings for each database. All searches essentially combine all terms found (and their truncated forms) for the foci of the search: palliative care and district nursing practice (Table 1).

<insert table 1 around here>

Papers were initially screened by title/abstract for relevance, and explored further if they appeared to relate to any aspect of the district nurses role in the provision of palliative care. Only papers in English are included, including papers studying community nursing work (the work of any nurse providing general home based nursing care) in any country. Papers are excluded if they examine specialist nursing roles i.e. specialists in palliative care or advanced cancer care. The search strategy was highly non-specific, returning many results that are irrelevant to the focus of the review. Additional search strategies included citation tracking, both to identify relevant papers citing earlier work, and to check the citations within identified papers for relevance, grey literature searching and additional snowball sampling to explore new propositions about district nursing care of those in the palliative phase of illness. There was a final search for studies as the review neared completion.

Initial database searches resulted in 2648 'hits in Medline, 1411 in Embase, 475 in PsychInfo and 2493 in Cinnahl. Most were rejected as not related to the review at the initial abstract screening phase, and once duplicates were removed 253 full papers were examined, which also included the papers identified from citation tracking. Sixty three potentially relevant studies were identified which contributed to the development of the statements about district nursing practice in box 2. For this final synthesis reported here we exclude two categories of papers (17 papers). First, studies which examine district nurses views on others' palliative care provision. Second, studies examining the educational preparation of district nurses to fulfil a palliative care role. These studies are not reported here because they are outside the scope of the review as they do not assist in understanding what district nursing care is provided to patients in the palliative phase of their illness. . Forty six studies which examine district nurse palliative care provision from the perspective of the district nurse and studies looking at such provision from the perspective of others (including patients and family carers) are included.

Quality appraisal

The guiding principle in a realist review is that any quality appraisal criteria should be subordinate to the usage to which the primary study is put, namely to appraise the contribution that each one makes to the developing synthesis (Pawson, 2006). Pawson (2006) argues that studies should be assessed against two criteria: relevance (has it appropriate content to add to the review) and rigour

(is the data being used for the review trustworthy). Pawson (2006) argues that the worth of the study is determined in the synthesis. Formal research appraisal tools are therefore not used in this review, but studies judged initially for relevance, and the quality of the evidence they provide assessed. Four questions were asked of research reports: quality and transparency in reporting (is the research presented in such a way that can be appraised and used by others?); methodological quality (is the research technically well executed?); appropriateness of the methods (does the research approach match the defined purpose of the study); and quality of the messages in the research (does the research address important policy and practice questions in a way that is both useful and useable) (Boaz and Ashby, 2003)?

Data abstraction and synthesis

First, studies were reviewed to identify information to contribute to the process of identifying implicit concepts and theories of district nursing and palliative care. Second, the studies were reviewed in detail to identify data which supports or refutes the theoretical statements developed, or which suggests additional issues not yet considered (see box 2). A data extraction summary was constructed to link the statements being interrogated to the evidence that supports, refutes or develops those elements from each study.

Rather than a 'summative verdict' a realist synthesis presents a more refined theory or model (Pawson *et al.*, 2005). The process of synthesis is therefore one of continuous adjustment and refinement of theory, as each element of the theory

is interrogated with reference to the evidence found. The findings of the review are therefore presented as evidence to interrogate, support or refute the initial statements (box 2). All relevant findings from the included studies are examined with reference to these initial statements. It is worth noting that the initial statements do not explicitly examine the work that district nurses undertake with family carers, but this is addressed within each heading as appropriate.

Findings

Forty six research studies or reviews were identified and used to interrogate the statements about district nursing practice. These are summarised in table 2. There are a preponderance of UK papers (33 UK, 8 Scandinavian, 3 Australian and 2 Canadian studies). Most studies focus on the district nurses view of their role (22 studies), with fewer exploring both district nurse and patient (4) or district nurse, patient and family carer (2) views. Six studies explore the family carers' views of district nursing, with fewer exploring both patients' and family carers' views (4), or patients views alone (2). Six studies are multi-professional, exploring district nurses roles along with other professionals such as GPs. Most studies use qualitative data collection techniques, with 33 using qualitative interviews (i.e. phenomenological interviews, focus group interviews) as their main form of data collection and six incorporating some form of observation. Eight studies use questionnaires.

<insert table 2 around here>

District nurses value and respect patients in the palliative phase of illness

One dimension of the role of the nurse in palliative care is valuing – having respect for the inherent worth of others, which leads to persistence in trying to help (Davies and Oberle, 1990). These elements are empirically supported by some but not all studies. Studies illustrate that district nurses have personal commitments to palliative care patients and a genuine desire to do good which influences their approach to care (Appelin *et al.*, 2005; Oudshoorn *et al.*, 2007; Sandgren *et al.*, 2007; Wallerstedt and Andershed, 2007; Öhman and Söderberg, 2004). This affects the context of the encounter and what district nurses bring to the care encounter (Berterö, 2002; Cartwright, 1991; Grande *et al.*, 2004). These studies provide evidence regarding structural components of quality, but not about the process or outcomes of district nursing care. It is noteworthy that most of the studies which support this statement are Scandinavian, few studies from other countries report data which explicitly supports this statement, although neither is it refuted.

Palliative care is important to district nurses

An aspect which could be related to ‘valuing’ which strongly emerges from a wide range of studies across countries is not valuing the patient to whom they are

providing care, but valuing the provision of palliative care itself. It is clear from many studies that most district nurses highly value the act of providing palliative care (Law, 1997; Luker *et al.*, 2000; Berterö, 2002; Andrew and Whyte, 2004; Burt *et al.*, 2005; Bliss and While, 2007; Sandgren *et al.*, 2007). However, the different levels of expertise and interest of district nurses means that this may not be true of all nurses (Addington-Hall *et al.*, 2006; Burt *et al.*, 2005). Indeed, many studies have small, purposive samples, which may mean that district nurses with a particular interest in palliative care could be over represented in these research findings (e.g. (Wright, 2002; Berterö, 2002; Kennedy, 2005).

It is suggested that, particularly in the UK situation, this valuing is because palliative care provision legitimates the use of core nursing skills, skills which may be rarely used with other patients whose basic care such as washing and dressing has been passed over to providers of social care (Griffiths, 1997; Goodman *et al.*, 1998; Luker *et al.*, 2000; Griffiths *et al.*, 2007; Goodman *et al.*, 1998). Nurses take pride in their perception that they provide a pivotal role in the provision of palliative care, although they feel this role is under- recognised and undervalued by others (Burt *et al.*, 2008).

Palliative care patients are clearly important to district nurses, and equally district nurses contribute to patients' satisfaction with palliative care, mainly because they are accessible (Brazil *et al.*, 2005; Higginson *et al.*, 1990; Fakhoury *et al.*, 1996; Grande *et al.*, 2004; Fakhoury *et al.*, 1996; Lecouturier *et al.*, 1999).

However the work of district nurses is absent from some interviews with patients and their family carers (Exley *et al.*, 2005), which may reflect the patterns of care from multiple providers that patients receive. It may be therefore that district nurses are not as important to patient satisfaction as palliative care patients are to district nurse job satisfaction.

The quality of district-nurse patient relationships is important and has a direct effect on the quality of patient care

The importance of the relationship between district nurses and palliative care patients is the statement supported by most studies, and is a core finding of much of the work reviewed here (Andrew and Whyte, 2004;Seale, 1992;McHugh *et al.*, 2003;Luker *et al.*, 2000;Bliss and While, 2007;Griffiths, 1997;Kennedy, 2005;Berterö, 2002;Wright, 2002;Law, 2007;Carter, 2008;Hills, 2000;Wright, 2002;Wallerstedt and Andershed, 2007;Stoltz *et al.*, 2006;Sandgren *et al.*, 2007;Öhman and Söderberg, 2004;Mcilpatrick and Curran, 2000;Mcilpatrick and Curran, 1999;Law, 1997). An issue is that few studies explore exactly what is meant by such a relationship, and what its purpose is to the nurse or patient. Whilst it is argued that the use of self in a therapeutic manner is considered critical to contemporary nursing practice (Rose and Glass, 2006), the object of such relationships seems to lie at the level of friendship or familiarity rather than therapeutic objectives. District nurses appear to befriend patients, rather than offer them overt counselling (Griffiths, 1997;Griffiths *et al.*, 2007) and some

nurses appear to be more adept at relationship building, possibly because of personal chemistry (Sandgren *et al.*, 2007; Hills, 2000).

Familiarity with district nurses is also important to patients and family carers, with patients and family carers reporting security and comfort because district nurses are easy to talk to (Grande *et al.*, 2004; McKenzie *et al.*, 2007; Wilkes *et al.*, 2008; Wilson, 1999; Jarrett *et al.*, 1999). Such relationships appear therefore to ease the business of care, oiling the wheels of nurse patient interaction, and creating easy going relationships between many nurses and patients. Such relationships may not have a direct therapeutic outcome, but where key quality indicators include patients' perspectives about care (Department of Health, 2008; Department of Health, 2005a), good relationships are likely to improve satisfaction with care.

Palliative care is holistic care

District nurses use a wide skill set when caring for patients, with particular strengths in the provision of physical care (Grande *et al.*, 2004; Wilson, 1999; Gerrish, 2008), giving information and care coordination (McKenzie *et al.*, 2007; Öhman and Söderberg, 2004; Luker *et al.*, 2003; Griffiths *et al.*, 2007; Latham, 2001); Kennedy, 2005; Griffiths *et al.*, 2007; McHugh *et al.*, 2003). Skill deficits are noted in symptom management (Dunne *et al.*, 2005; Wilson, 1999) and managing psychological issues (Dunne *et al.*, 2005; Griffiths,

1997;Griffiths *et al.*, 2007;Trueman and Parker, 2006;Grande *et al.*, 2004;Wright, 2002;Wilson, 1999;Gerrish, 2008). Nurses and patients have particular perceptions of care, expecting and having confidence in nurses physical care, knowledge and expertise (McKenzie *et al.*, 2007;Öhman and Söderberg, 2004;Luker *et al.*, 2003). However, patients also report feelings of powerlessness, counterbalanced by reporting wishing district nurses to coordinate their care, and being reluctant to ask for help (Wilkes *et al.*, 2008;Jarrett *et al.*, 1999). These tensions may reflect a lack of clarity about the district nurse role, with expectations that they will both be an advocate for patients, and simultaneously foster participation in their own care (Luker *et al.*, 2003).

District nurses appear to particularly struggle with psycho-social aspects of care. Some studies describe district nurses helping others prepare for death, through their presence and showing they are not afraid (Öhman and Söderberg, 2004) and giving and receiving affirmation (Stoltz *et al.*, 2006). However, more studies discuss district nurses having difficulties in communicating effectively with dying patients, finding it awkward and uncomfortable, not knowing how to respond. This can lead to district nurses distancing themselves from patients and their families, avoiding meaningful conversations and probing patient concerns, using blocking tactics and finding truth telling difficult (Dunne *et al.*, 2005;Griffiths, 1997;Griffiths *et al.*, 2007). District nurses argue that they don't have the psychological training or experience to open 'the can of worms', with concerns

about exposing issues if they haven't got the training to deal with them (Trueman and Parker, 2006).

Palliative care can be stressful and emotionally difficult

Many studies identify the emotional stress that district nurses experience derived from caring for patients at the end of life (Andrew and Whyte, 2004;Seale, 1992;Rose and Glass, 2006;Dunne *et al.*, 2005;Berterö, 2002;Goodman *et al.*, 1998;Sandgren *et al.*, 2007), frequently exacerbated by inadequate resources, time or knowledge (Andrew and Whyte, 2004;Berterö, 2002). There is a clear link with the strength of feeling district nurses have about developing a relationship with patients, as such relationships can be demanding, with nurses reporting finding it difficult to leave and take time off (Griffiths, 1997).

It is perhaps self evident that staff dealing with those who are dying are likely to find it stressful, however generalists such as district nurses identify particular issues because of the difficulties of providing palliative care amongst all the other calls on a district nurses time (Burt *et al.*, 2005;Seale, 1992;Burt *et al.*, 2008;Wallerstedt and Andershed, 2007;Berterö, 2002;Öhman and Söderberg, 2004;Rose and Glass, 2006). District nurses appear to cope with this by giving additional time to palliative patients within a general caseload, rationalising that the caring situation is going to end (Stoltz *et al.*, 2006).

Home is important as a care context.

The concept of home care appears important to district nurses, as the core place in which they deliver much of the care they offer. The research examined suggests that the home context is important as it affects the structure of care in terms of power relationships and the way district nurses must adapt the care they give (Appelin *et al.*, 2005; Stoltz *et al.*, 2006; Wilkes *et al.*, 2008; Goodman *et al.*, 1998). However, there is also a perception that giving care within the home affects valued outcomes of care such as preventing hospital admissions and influencing place of death (Burt *et al.*, 2008; Öhman and Söderberg, 2004; Rose and Glass, 2006). However, as with much of the research in this review, there is no evidence presented that district nurse care in patients' homes actually has an impact on such outcomes, only that people perceive that it is likely to have such impacts.

District nursing care is invisible.

District nurses consider that district nursing care is invisible, both because it happens at home, behind closed doors, and because the role is not acknowledged by others (McHugh *et al.*, 2003; Brocklehurst and Butterworth, 1996). District nurses clearly describe the way that their work is hidden in the home and that their role as a provider and coordinator of care is unrecognised within the hierarchy (Goodman *et al.*, 1998), that their work is not valued, and the

range of skills they provide is not appreciated (Hills, 2000;McHugh *et al.*, 2003). It seems that palliative care is one area where district nurses strive to emphasise the importance of their work and take authority from this, however it has been argued that it is the dying patient's need that is visible, not the work that the district nurse does or the skills that they use in providing care (Burt, 2005). The invisibility of district nursing care and services have long been highlighted as an issue (English National Board and Queens Nursing Institute, 2002), but with little apparent change.

District nursing service is demand led.

District nurses talk about the demands of referrals, and particularly some of the inadequate referrals they receive and the desire to receive early referrals (Austin *et al.*, 2000;McHugh *et al.*, 2003). However, this statement is not particularly supported by the evidence reviewed. What district nurses do discuss is the element of time, and having and making time for patients, rather than the service being demand led. However, creating time, when combined with workload difficulties, time constraints and inadequate resources can be associated with stress (Wallerstedt and Andershed, 2007).

Relationships with colleagues are important

Partnership working with others is increasingly seen as a core health provision concept within and out with palliative care (Department of Health, 2002; National Council for Hospice and Specialist Palliative Care Services and National Association for Health Authorities and Trusts, 1998). The research reviewed here suggests that district nurses see themselves coordinating the work of others, having control of the caring situation (Goodman *et al.*, 1998; Carter, 2008; Kennedy, 2005; Luker *et al.*, 2000; McHugh *et al.*, 2003; McIlpatrick and Curran, 1999; Burt, 2005; Berterö, 2002). Rather than partnerships, relationships are frequently referred to as poor or challenging, and there can be a reluctance to involve others in patient care (Dunne *et al.*, 2005; Law, 1997; Luker *et al.* 2000). District nurses appear conflicted, both supporting the importance of working with others to promote best quality care, but clearly identifying the difficulties of this and a desire to be the primary professional carer.

Discussion

This synthesis identifies much evidence which mostly supports the initial statements presented (box 2), which could be seen as self evidently important issues for district nursing and their provision of palliative care. There is congruence with the findings of the earlier review (Bergen, 1991) in terms of district nurses conceptualizations of their strengths and weaknesses, but less development of an understanding of the way they work and the outcomes of care than might be expected. The value in this synthesis lies in the novelty of the

realist review and in identifying what is and is not known, and in highlighting future practice and research priorities in this field.

Strengths and limitations

The evidence presented in this review has particular strengths and weaknesses. It has strengths because the review draws upon a large number of studies investigating the area of district nursing roles in the provision of palliative care. Data from 46 research studies that explore district nurses' and patients' views on the district nurses' role in the provision of palliative care are synthesised. There is particular breadth in the literature exploring district nurses own opinions and voices about providing care to this patient group, with three quarters of the reviewed studies capturing some element of the district nurses voice and opinion on this issue. Most of these are qualitative studies, enabling a rich and detailed exploration of what it means to be a district nurse with patients who are dying. Many of these studies identify similar issues, highlighting the important and widespread nature of issues such as relationship building with patients. However it could be concluded that we do not need any more small scale qualitative studies on this subject but rather a coherent programme of work that focuses on outcomes and impact of the service.

Whilst there is strength in the wide number of studies from which this review draws, there are also limitations to much of the research reviewed. First, few studies examine the patients' or family carers' views on district nursing services, and even fewer integrate the opinions of both patients and nurses within the

same study. Second, many of these studies are small, poor quality research, often qualitative interview studies with few participants. A strength of this realist synthesis is the ability to use these small studies, which might be individually perceived as of poor quality, as data to support or refute the propositions developed about district nursing care. Third, there are more studies examining structural issues (e.g. the context of the encounter and what district nurses bring to care), than examining processes (what care district nurses provide), or outcomes of care (what contributes to the quality outcomes of district nursing care). Forth, related to the above issue, most of these studies use interviews as their primary or only data collection method. This enables exploration of what district nurses say they do, or would like to do, but does not enable exploration or understanding of what they actually do in practice, and their impact on the outcomes of care. It is clear that more observational studies, studies which explore care outcomes, and studies testing interventions to improve care outcomes are required. Fifth, there isn't clarity on the international nature of such home based nursing care. There is no universal definition of a 'district nurse', and whilst a judgment was made that any study reporting non palliative care specialist nursing care of patients at home would be included, a lack of contextual data in many of the included studies means that the actual services themselves may be different. Studies are mainly from the UK, Scandinavia and Australia, which probably reflects the service provision patterns in these countries.

The applicability and implications of the findings

Strength of support for the statements guiding this review varied, but none are refuted by the evidence examined. The assumption most strongly supported is the importance of the district nurse - patient relationship. To district nurses this relationship seems core to the way they enact care with palliative care patients, and the process by which they provide quality care. Such attitudes are not unique to district nursing, with palliative care professionals reporting the importance of authenticity as a core professional attitude, manifesting itself in relationships with patients and others (Simon *et al.*, 2009). Whilst patients value familiarity with district nurses, they don't discuss relationships in the same way that district nurses do. However, a real issue with this research, exemplified by this theme, is that studies to date do not have the potential to inform district nursing practice. Much is assumed about the realities of nursing practice, but there is little explanation of how care is provided, and our knowledge of the impact of nursing care in this context is unknown.

Whilst the research clearly states, for example, that the nurse-patient relationship is self evidently important to district nurses, little research explores this relationship further to examine the consequences of care where such relationships don't exist, what the exact value of the relationship is to nurses, patients and family carers, how nurses go about forming such relationships with patients, and perhaps most importantly, the impact of such relationships to both care processes and outcomes. It is not known whether forming a relationship with patients is a worthwhile care outcome per se, or whether the importance is because the relationship impacts on other care outcomes.

There is therefore insufficient evidence to recommend that building a close relationship with patients and family carers is a necessary precursor to desired care processes and outcomes. Just because it is important to district nurses, does not necessarily make it a vital element of care, although neither can it be decided that it is unimportant to care outcomes. District nurses themselves identify relationships as an indicator of quality processes, but when identifying indicators of quality outcomes of care specify issues such as place of care and death, symptom control, and comfort without directly relating this to the presence of the relationship (Austin *et al.*, 2000). Again, other palliative care professionals indicate the fundamental importance of relationships and attitudes to care, stressing the importance of professional-patient relationships, nurse personalities, and the approach to care (Simon *et al.*, 2009; Gambles *et al.*, 2003). Nurse/patient relationships are clearly important to nurses, and may be valuable to patient outcomes, but this is not proven in the research reviewed here.

There are similar issues with the relevance and applicability of the strong support for the statement that district nurses value and prioritize the provision of palliative care to their patients. Whilst this prioritisation may enhance the care of palliative care patients, it is not known whether this is in fact the case, nor the impact on non-palliative care patients on the district nurse caseload. Again, this prioritisation is likely to have clear benefits for the district nurse, gaining acceptance and status from the kudos of caring for dying patients, to counter their general impression of themselves as invisible and undervalued (Livesey,

1998;Glendinning *et al.*, 2002;English National Board and Queens Nursing Institute, 2002). District nurses are generally unclear about how their work fits into the policy agenda and where focus of their role should be (Bennett and Robinson, 2005;Madsen, 2009), and possibly they find the provision of palliative care at home as a role that they can 'own'. Other professionals do acknowledge the important role of district nurses in palliative care provision (Walshe *et al.*, 2008), but this is not a universal finding, with one survey finding that 66% of London based GPs disagreed with the statement that palliative care is mainly district nursing work (Burt *et al.*, 2006).

The research in this field to date therefore provides clear evidence that palliative care is important to district nurses – they value its provision, they value developing relationships with patients, they consider themselves pivotal to palliative home care, but acknowledge that it is difficult and stressful work. There are elements of this work that they find more straightforward (such as physical care), and more difficult (such as emotional care), although district nurses vary in their interest and expertise in palliative care. Patients clearly find district nursing care important because nurses are friendly and available. However, there is little evidence that could provide a clear guide to district nurses aiming to provide care to palliative care patients known to be either important to patients or critical to improving care outcomes. In relating this to the aims of this review, much of the research reviewed does not allow us to understand the role of the district nurse in

their provision of palliative care, but rather the views of district nurses on the importance of palliative care provision.

It is therefore not possible, on the basis of the research reviewed to reformulate the initial statements about district nursing practice into a model to guide district nursing practice roles. Not because the statements are not supported by the evidence, but because the statements generated from this literature either do not have utility to guide practice, or cannot be interrogated in a way that has utility.

Recommendations for further research

This synthesis highlights clear gaps in our understanding of the way district nurses provide palliative care. Many of these gaps are because there is a predominance of small scale interview studies focusing on district nurses views on palliative care. Instead, studies should focus on a wider range of questions, using a variety of research methods to inform improvements in district nursing practice. Particular recommendations include:

- More research involving patients and family carers, particularly that which studies patients, family carers and district nurses. The patient and family carer view on district nursing care is particularly absent, and their views are critical to our understanding of what constitutes quality care in this setting, as it is clear that their views can differ from 'experts' (Carter *et al.*,

2004). Indeed, there should be an interest in family carers in their own right as recipients of district nursing care.

- Research which is inter-professional, and which looks at the outcomes of real life care provided by a complex web of professionals (Corner, 2003).
- More research using a wider range of research methods. In particular observational methods are required to investigate in more depth and detail what district nurses actually do in practice, as opposed to their views about what they do, and methods which explore the outcomes of district nursing care, and the impact of particular care models on outcomes such as place of care and death, symptom control and patient satisfaction.
- Research which has a clear theoretical underpinning.

Information on patient preferences and nursing practice can then be fed into research on models and approaches to district nursing palliative care and their impacts on outcomes of care.

Conclusion

It is not possible to conclude from this review what constitutes excellence in district nursing practice with palliative care patients in terms of care processes and outcomes that are valued by patients, although there is a very clear consensus from district nurses about what they consider to be important in the way that care is provided. Because of this there is no attempt to build the statements guiding this synthesis into a more developed theory of district nursing

practice in palliative care. What is clear from this synthesis is what we already know about district nursing palliative care, and most importantly a clear direction for future research to inform district nursing practice in ways known to improve care. District nursing research with palliative care patients needs to be re-conceptualised in a way which clearly drives forward district nursing theory and models for practice, as current implicit assumptions about practice which underpin studies are insufficient or insufficiently realised to be useful.

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District nurses and their provision of palliative care. Tables and figures

Country	Term	Role
UK	District Nurse	Qualification: Registered nurse with additional community focused qualification. Role: Nursing care primarily in domestic home settings. Typically assess, plan and deliver nursing care for those with acute, chronic and life-limiting conditions across all age ranges.
Australia	District Nurse	Qualification: Registered nurse, no additional formal qualification required. Role: Mostly generalists, but some specialist services provided. Work primarily in domestic home setting providing wound care, diabetic care, medicine management, palliative care and monitoring (Annells, 2004).
Canada	Community Health Nurse (which describes two core functions, home health nurse and public health nurse)	Qualification: Registered nurses primarily educated to degree level. No additional formal qualification required. Additional Community Health certification is available. Role: Plan, deliver and evaluate care of acute, chronic and terminally ill clients in community settings (e.g. wound care, palliative care, care of IVs, respiratory care). Some home care programmes have specialist provision i.e. in palliative care. (Victorian Order of Nurses, 2010; Community Health Nurses Association of Canada, 2008)
US	Home care nurse	Qualification: Registered nurse. Care provision can facilitate access to a home health aide (non-registered nursing assistant). Care must be ordered by a physician. Role: Provision of skilled, intermittent nursing care under a home health care plan, provided by a home health agency. (Centers for Medicare and Medicaid Services, 2007)
Sweden	distriktsköterska (District nurse)	Qualifications: Licensed nurse with additional qualifications in district nursing/community health. Role: Nursing care at home or in clinic or other community settings across all age ranges. Nursing care can include medicine management, monitoring, wound care, equipment provision, counselling etc. (National Organisation of District Nurses, 2008).

Box 1. Terms used to describe generalist registered nurses providing home care across different countries

Search terms for district nursing <i>and</i>	Search terms for palliative care
All combined with <i>or</i> District nurse Home health nursing Community nursing staff Home care services Home visiting Home visiting programs Public health nursing Community health services	All combined with <i>or</i> Palliative Palliative care Terminal Terminal care Terminally ill Terminal care services End of life End of life care Hospice Hospice care Hospice and palliative nursing

Table 1. Literature search terms used.

- 1) District nurses value and respect patients in the palliative phase of illness.
- 2) Palliative care is important care to district nurses.
- 3) The quality of district nurse - patient relationships is important and has an effect on the quality of palliative care.
- 4) Palliative care is holistic care.
- 5) Palliative care can be stressful and emotionally difficult.
- 6) Home is important as a care context.
- 7) District nursing care is invisible.
- 8) District nursing service is demand led.
- 9) Relationships with colleagues are important

Box 2. Statements about district nursing practice with palliative care patients drawn from textbooks, policy and research.

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
Andrew and Whyte (2004) UK	To explore experiences of DNs caring for people receiving palliative chemotherapy	Structured interview using critical incident	10 DNs (from 46).	Stressed role of DN throughout cancer journey, knowing patient and family, hospital interface, perceptions of palliative chemo (ambivalence), uncertain ground. Building a relationship.
Appelin et al. (2005) Sweden	To explain and describe a complex picture of how people involved in the palliative care of cancer patients at	Phenomenological Interviews	6 cancer patients receiving care at home, 6 of their next of kin, 6 DNs caring for those patients	Advantages of home care: Striving for a normal life (care in the home, emotional experiences, safety, resources/policies) Disadvantages: Commitment (adaptation and extra work) and

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	home experience this			demands (frustration and uncertainty).
Bertero (2002) Sweden	The meaning of palliative care as experienced by district nurses	Phenomenology – interviews	6 DNs.	Four themes: challenge (structuring tasks difficult, knowing what to do), control (over caring situation), frustration (not giving care they would like), relationships (to create and maintain relationships with patients). Essence of themes is commitment.
Bliss and While (2007) UK	To explore the different ways that DNs and SWs work in	Case study approach with case being the 'package of care for	8 cases.	Five themes: Assessment (DNs assessed most referrals, SWs only those screened by support staff).

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	providing packages of palliative and continuing care	service users having provision from both DN and SW'. Interviews, documentary analysis, observation of case conferences.		Care delivery (DN actively provided care, SW managed provision of care by others). Focus of care (DNs concerned with achieving optimum well-being for service users, SWs with ADL and maintaining users within own home). Place of care (both identified care should take place in most appropriate environment, DNs more likely to advocate change to place of care from home environment). Funding of care (DN free at point of delivery,

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				SW limited resources with cost implications).
Brazil <i>et al.</i> , (2005) Canada	To describe service preferences among informal carers of the terminally ill.	Telephone interviews with carers when patient designated as palliative and 5 months later. If patient died, caregiver interviewed 3 months after death.	376 caregivers	90.7% reported in-home nursing care as most valuable (the most valuable service noted). 8% would have liked more in home nursing. Most perceived service needs were of a supportive nature.
Brocklehurst and Butterworth (1996) UK	To explore the role of the DN in the care of people affected by HIV infection. To	Multiple case study (3 cases) focused on cities providing care to HIV patients. Data collection	476 service users and 128 hospital and community staff.	Mostly referred for physical problems such as medication, wound care etc. Most time consuming element of care was related to emotional needs.

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	identify ways of improving home care for people affected by HIV infection.	methods: discharge surveys, district nurse survey, user focus groups.		Improvements suggested were more resources, better communication, more education, and increased support and supervision.
Burt et al; (2005) UK	To explore the realities of providing palliative care in the community to help PCTs commission pc services effectively.	Map provision, explore attitudes to provision, investigate how GPs and DNs work with specialist palliative care, understand priorities of participants.	5 PCTs, with info gathered from 565 people. Needs assessment, 9 focus groups, postal questionnaires to each DN and GP (57% GPs – 354 from 620), 52% DNs (179	Wide variations in practice, and differing perspectives on others roles. DNs felt they had a pivotal role. Saw pts most frequently. Other participants agreed, except GPs, 2/3 of whom thought pc was not mainly DN work. Time consuming and complex work. Priority area for DN and GP was daytime DN care.

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
			from 341). 32 semi-structured interviews.	
Burt et al (2008) UK	To explore community nurses' perceptions of their palliative care role, and their provision of such care within the context of their wider generalist caseload	Focus group study	Four PCTs in London. Purposive sample of 51 community nurses. Nine focus groups (4-7 participants in each).	Five themes: Felt had a central role in pall care provision at home. Role not recognised by other hcps and managers. Pall care unpredictable and time consuming, pressurized context with staff shortages and lack of time. Pall care rewarding, but took toll on emotions, lack of formal support. Doing pc within a generalist caseload created additional

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				pressures.
Carter (Carter, 2008) UK	To understand community nurses' experiences and perceptions of their role	Qualitative interviews	11 DNs (from 13) across 2 PCTs	Building a supportive network (DN service accessible, flexible, rapid, supporting informal support, referring on). Emotional labour (dealing with expectations, creating a good death, building relationships) Negotiating community care (GP partnerships, recognising dying)
Cartwright (1991) UK	Views of balance of care between hospital and community for	Questionnaire or interview study with professional carers of	245 GPs (62%), 211 hospital consultants (65%), 92 DNs (92%).	Wanted to see more care in peoples homes. Home help services in adequate. Desire for more services

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	those who are dying	800 randomly selected deceased persons	Of the 92 interviewed 82% were DNs.	overnight. Concerns re adequate pain control,.
Dunne et al. (2005) UK	To explore DNs experiences of providing palliative care for patients with cancer and their families	Phenomenological interviews.	Purposive sample of 25 female DNs (at least 20% of caseload palliative, cared for pc in last 6 months) – from a potential sample of 125.	Four main themes: challenges for the DN in symptom management, the communication web, the family unit as an element of care, personal cost of caring
Exley et al. (2005) UK	To establish the challenges of identifying and meeting the needs of	Qualitative semi- structured interviews with those dying and lay carers. Focus group with	29 patients (50 interviews) within two general practices. No data given on focus	References to DNs noticeably absent from interviews with patients and their carers. Those with cancer more likely to receive DN care. DNs

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	people dying in the community of both malignant and non-malignant disease.	DNs, GPs, specialist pall care nurses and OTs	group participants.	felt heart failure referrals only came at 'crisis point'.
(Fakhoury <i>et al.</i> , 1996) UK	To examine association between informal caregivers' satisfaction with district nursing services, and service and non service variables.	Analysis of sub sample from Regional Study of the Care of the Dying.	1858 relatives or close friends of people who died from cancer.	59% had home care from a DN in their last year of life. 87% satisfaction with DNs. Those highly satisfied with DN services reported more visits, more frequent visits, that DNs contacted other services, DNs helped at night, and DNs visited bereaved caregiver.
(Gerrish, 2008) UK	To examine how	Ethnographic approach	26 weeks of	Rationale for family carer support

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	district nurses interpreted the ideology of individualised care in their everyday practice.	incorporating participant observation and interviews	observation with 6 district nursing teams (2-3 days/week) plus 12 interviews.	(part of role, need family carers help, but not on caseload of own right), Assessing and responding to carer needs (no formal assessment. Role enabling, supporting, mediating, carer substitution, crisis prevention, crisis intervention, (for those dying, DNs accepted need for ongoing and increased involvement in direct care).
Goodman et al (1998) UK	How do district nurses define and experience their work following a	Collective case study. Semi-structured interviews with DNs,		Terminal care valued by DNs, and used to define DN care by DNs and GPs. Source of job satisfaction.

Author, Date, Country	Research question/theme	Research approach	Participants	Findings/outcomes
	policy change (GP fundholding)	GPs, managers. (12 trusts, 60 participants). Then fieldwork with two practices in two trusts. (interviews and observation)		Sanctioned nursing activities that would otherwise be social care. DNs in control of patient care for pall care patients, and responsible for delivery and coordination of care. Nurses took authority from the fact that they were caring for dying patients. Enjoyed care. Terminally ill patients need is visible, not the work that DN does. Terminally ill patients narrowly categorised.
Goodman et al (2003b)	To investigate the district nurse	Focus groups with DNs and care home	89 DN team leaders (76%), 96 managers	Palliative care an area of care which provoked debate and lack of

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
UK	contribution to palliative care in care homes	managers. Questionnaires to DNs and care home managers.	(71%).	consensus in such care. Fewer than half of care homes said DNs involved with dying residents. Often need specific (i.e. equipment). Often not directly involved with care. Difficulties because of high turnover of care staff. Few wanted to develop work in this field.
Grande et al. (2004) UK	To identify what informal carers valued in the palliative support provided by GPs and DNs.	Retrospective semi- structured interviews.	Bereaved carers of 48 patients with cancer, and 12 patients with non- cancer.	Accessibility of GP and DN most important aspect of support. Help from other agencies and provision of equipment also important. Attitude during interactions, and relationship

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				with professional important (partic GP). Main focus was basic support that enabled them to sustain care in the home.
Griffiths (1997) UK	Ethnographic study of district nursing work	Ethnographic interviewing and observation.	130 observations of 37 G and H grade DNs from 3 community trusts. 50 semi-structured interviews.	Terminal care sanctioned holistic care incl. social care. And also sanctioned the 'support' visit. Possessive about patients. Highly valued work.
Griffiths (2001) UK	To identify who community nursing staff contact when	Survey to all district nurses within one NHS trust	71 responses (46%)	Contacts frequently with patients own GP, Macmillan nurse, or caseload holder. Sometimes lack of

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	needing to discuss an aspect of palliative care			clarity about the satisfactory nature of the advice.
Griffiths et al. (2007) UK	How do DNs perceive their role in supporting cancer patients with palliative care needs at home.	Qualitative approach with semi-structured interviews	34 DNs	Importance of DN involvement in early supportive phase from DN perspective. Relationship building. Difficulty in articulating support. Appropriate? Able to deal with emotional support?
(Higginson <i>et al.</i> , 1990) UK	To investigate the current problems and needs of terminally ill cancer patients and	Prospective questionnaire study. Rated 8 current problems and comments	65 patients, each with a member of their family or a carer.	District nurses were rated as good or excellent by 71% patients and family members.

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	their family members, and to discover their views of hospital, community and support team services.	on staff after minimum of two weeks care from palliative care support teams.		
Hills (2000) UK	To explore the supportive role of the DN in care of terminally ill patients and their families	Focused interviews	10 DNs in one community trust	<i>The nursing relationship.</i> Vital to supporting patients (being informal, honest, reliable, trust, being concerned, respecting) They practiced 'being there, availing and being flexible. . <i>Being professionals</i> through

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				<p>performing the nursing process.</p> <p>Slightly removed, to carry burden.</p> <p>Facilitating coping Challenging levels of understanding, intervening in relationships, easing stress.</p>
Jarrett <i>et al.</i> , (1999) UK	Views of patients and lay carers on community based services.	Interviews with patients	21 participants. Lay carer n=11, patient n=9.	<p>Three themes: the providers of care (role perceptions and domains of responsibility), economic and practical problem or needs, continuity of care and communication.</p> <p>Perceptions of DN role: valued role,</p>

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				flexible, and responsive to changing needs.
Kennedy (2005) UK	To examine DNs ongoing care for patients with cancer requiring palliative care, and to illuminate issues which impact on care planning by DNs.	Qualitative case study – observation of visits to patients, interviews	3 patients and 3 DNs (11 observation visits, 12 interviews).	Importance of knowing the family. Establishing relationships with patients and carers. Importance of early referral. Knowing who knows what. Getting the balance right. (sharing information, sharing care, knowing what might happen in future).
Latham (2001) UK	To understand DNs understanding of the needs of cachectic	Phenomenological qualitative interviews	10 DNs interviewed from one HA.	Nutrition (exhortation to eat more), causes of lack of appetite, pressure area care, causes of cachexia, body

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	patients at home			image. Lack of knowledge of physiology.
Law (1997) UK	District nurses understandings of their terminal care practice	Semi structured interviews and observation	6 DNs interviewed, with observation of practice of 4 nurses.	Treat all pts same irrespective of diagnosis, but aware of better services for cancer pts. Defined good terminal care as: establishing good relationships, ,effective control of pain and other symptoms, involving patients in their own care, working relationships with GPs.
Law (2007) UK	How district nurses meet the emotional needs of their dying	Grounded theory. Observing interactions between DNs, patients	12 DNs, 9 patients, 4 family carers, books of 5 dying authors.	Five categories: dying world, outside world, entering dying world, maintaining connections between

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	patients in the community.	and carers. Interviews.	9 observations and 19 interviews in total.	worlds, and core category of bridging worlds. DNs meet emotional needs by entering their dying world. Three properties for entering dying world: establishing relationships, identifying emotional needs, and enabling emotional expressions.
Lecouturier <i>et al.</i> , (1999) UK	To assess the satisfaction of lay caregivers with the care received in the community by those dying of cancer	Postal questionnaire to carers identified through death register, sent 3 months after death.	156 carers (44% response).	63% had had help from a DN (34% mac nurse, 13% marie curie nurse). Most reported receiving sufficient help given when most needed. Most felt nurses knew enough about patients condition. More frequent

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				visits = more satisfaction.
Luker et al. (2000) Austin et al.(2000) UK	To identify community nurses perceptions and definitions of quality care provision for palliative care patients	Interviews with community nursing staff (all grades), using a critical incident approach.	62 community nurses, describing 120 incidents relating to palliative care.	Structures: early referral, family circumstances, availability of time, availability of services and equipment. Processes: relationship with patient and family, relationship with other healthcare professionals and formal carers. Outcomes: patients/family and the DN team (i.e. care in place of choice, control, quality of life, symptom control, able to cope, done a good job)
Luker <i>et al.</i> , (2003)	To identify the roles of	Qualitative interviews	27 patients (and their	Main themes: perceived roles of

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
UK	district nurses and community services as perceived by patients with cancer and their carers before and after hospital discharge		carers) gave rise to 71 interviews (34 predischARGE 26P, 8C), (37 post discharge (22P, 15C).	district nurses(Didn't know what needed DN for, stereotyped physical role), interface with others (associated with helpful/unhelpful GPs, can't differentiate between DNs and Mac nurses,
McHugh et al (2003) UK	To explore DNs perceptions and experiences of referral of cancer patients	Interviews	20 DNs	Concerns regarding completeness, accuracy and appropriateness of referral. Wanted all patients with cancer referred to them. Wanted to build relationships with patients. Keen to coordinate care and be the

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				main care provider.
McIlpatrick and Curran (1999) (2000) UK	To investigate and evaluate DN's perceptions of palliative care services within two community trusts in Northern Ireland	Stage 1: Focus groups with DNs. Stage 2: Questionnaires to all DN sisters in two community trusts.	Two focus groups (N=6 and n=5) 66 of 68 (97%) DNs	Stage 1: DNs felt they had a key coordinating role, and provided much supportive care. Importance of relationships. Some problems communicating with other profns. Stage 2: Most respondents considered DNs role was very wide, incorporating many different elements of care. Time could affect service provision.
McKenzie et al	To understand the	Observation of	19 patient and 12	<i>A sense of security</i> : Nursing visits

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
(2007) Australia	relationship between RNs working in the community and their cancer patients.	patient/nurse encounters, qualitative interviews with nurse and patient	nurse participant interviews, 19 observed encounters, 19 patient interviews, 38 nurse interviews.	gave security, reassurance and confidence. <i>Confidence in nursing expertise and knowledge:</i> Comprehensive assessment, confidence to manage self care.
Ohman and Soderberg (2004) Sweden	To elucidate the meaning of district nurses experiences of encounters with people with serious chronic illness and their close relatives in	Narrative interviews with district nurses (phenomenological approach)	10 DNs	DNs experiences of encounters with people with serious chronic illness are understood as DNs being welcomed into ill person's privacy, to share intimacy and understanding of being ill. Three themes: being in a close relationship; sharing an

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	their home			understanding, and weaving a web of protection.
Oudshoorn et al. (2007) Canada	To elicit an in-depth understanding of the sources of power and how power is exercised within client-nurse relationships in home-based palliative care.	Secondary qualitative data analysis from an in-depth ethnographic longitudinal study of nurse-client relationships.	33 transcripts with nurses and patients.	<p>Hierarchy of power within home based pc.</p> <p>Macro: nurses powerlessness – fiscal pressures, regulations.</p> <p>Meso: nurses exercise professional power – assessing, monitoring, controlling client care. Ownership.</p> <p>Facilitated client empowerment.</p> <p>Meso: clients' exercise of personal power – Not following plans.</p> <p>Micro – clients' experience of</p>

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				powerlessness – lack of continuity, lack of time, nurses going against wishes.
Palsson et al. (1995) Sweden	To illuminate district nurses' experiences in the home care of cancer patients.	Qualitative interviews	39 district nurses participating in a training programme (from 62 nurses available).	Main themes: Daily dressings of ulcerous cancer wounds, managing physical pain, being too close to the patient, not being allowed to communicate openly, not being allowed to help, patients trust in alternative medicine, being accepted as a helper.
Rose and Glass (2006) Australia	A review of literature to explore	Literature review (1995 – 2005). No specific	No data on number of studies reviewed	Biomedical and holistic paradigms: tension between

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	philosophical underpinnings of community nursing in Australia, and to critique contemporary issues facing community nursing, palliative care nursing and community nursing palliative care focusing on quality of care and sources of stress related issues.	method of literature synthesis specified. Search focused on emotional well being terms.	given.	<p>biomedical model of care and preferred contemporary approach to holistic care.</p> <p>The burden of health care: Early discharge, move to primary care etc. placing pressure on community nurses.</p> <p>Humanistic and multiplicitous roles: Take account of multiplicity of patients circumstances to empower patients. Quality practice requires trusting, open, sensitive and confident engagement with patients.</p>

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				<p>Use of 'self' in care. Nurses marginalised and less visible than other nurses.</p> <p>Negotiating emotional care: There are 'being' and 'doing' roles.</p> <p>Community palliative care: quality of care affected by cancer or non-cancer diagnosis. Believe make a valuable contribution. Invisible.</p> <p>Understaffed, but prioritised pc.</p> <p>Professional isolation.</p>
Sandgren et al. (2007) Sweden	To develop a grounded theory of	Qualitative interviews (and secondary analysis	32 nurses (and 11 interviews	Desire to do good is the main motivation for caring. Responsibility

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	palliative home nursing care. What is the main concern for community nurses caring for palliative cancer patients and how do they resolve it?	of data collected in earlier studies to refine categories)	with community nurses, 3 focus groups with community nurses, surgeons and GPs)	to patients. Anticipatory caring: doing best, foreseeing trajectories, creating trust, collaborating, prioritising. Momentary caring: doing best, temporary, solutioning. Stagnated caring: doing what is expected, avoiding changes, resigning.
Seale (1992) UK	To explore DNs provision of palliative care, their own view of terminal care, and	800 deaths in 10 areas of England, dying in Oct/Nov 1987. Interviews with person who knew	639/800 respondents (80%) 280 nurse episodes,	12% needed nursing help and didn't receive it, 22% wanted help more often. Lack of time a barrier to DNs, but not always acknowledged when

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	relationships with other professionals.	deceased best. Questionnaires with HCPs involved in caring regarding nurses general views on terminal care, and specifically about care of patient.	with 92 answering gen questionnaire, and 113 pt questionnaire.	considering particular patients. Didn't always recognise when pts would have liked more nursing help. Areas of tension in DN relationship with GP.
Stolz et al. (2006) Sweden	To illuminate the meaning of being supportive to family caregivers who care for a relative at home	Phenomenological with registered nurses working in 'advanced home care'	20 RNs	Two core themes: 'forming a relationship' (striving to build a trustful relationship, being a confidant, being attentive to needs) and 'keeping caregiving at home' .

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	as narrated by registered nurses.			(striving for preparedness, sharing reciprocal affirmation, experiencing opposing demands, balancing caregiving responsibility, facilitating care giving, reassuring, encouraging).
Törnkvist <i>et al.</i> , (2000) Sweden	To investigate patients satisfaction with the care given by district nurses at home.	Questionnaire (Quality of care from the patients perspective).	168 adult home care patients and 264 outpatient clinic patients	Measured four dimensions: 'medical/technical competence', 'physical technical conditions of care organisation, identity orientation in the attitudes and actions of the district nurses, and the socio-cultural atmosphere of the care organisation,

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				and the perceived accessibility of nursing care. Needing improvement: pain, safety of home, participation in decision making, care not always based on desires and needs.
Trueman and Parker (2006) UK	To understand community nurses' understanding of life review as a therapeutic intervention for younger people requiring palliative	Focus group interviews with generic and specialist community palliative care nurses.	21 respondents in three focus groups.	Limited knowledge about life review, confused with reminiscence. Believed could cause harm to practitioners. May be useful with training. Life review needed a relationship based on trust.

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
	care			
Wallerstedt and Andershed (2007) Sweden	To describe nurses' experiences in caring for ill and dying patients outside special palliative care settings	Phenomenological interviews	Nine nurses from district nursing, home care/nursing home care and hospital care.	<p><i>Ambition and dedication:</i> Positive attitude to care, and high ambitions and special interest in end of life care. Goal for pt to get best care. Needs dedication and knowledge.</p> <p><i>Everyday encounters:</i> responsibility, cooperation, experience and knowledge, feelings, time and resources.</p> <p><i>Satisfaction and dissatisfaction:</i> Satisfaction to give care to ill person, holistic. Dissatisfaction due to lack of</p>

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
				time and support.
Wilkes <i>et al.</i> , (2008) Australia	Clients with chronic and complex conditions: their experiences of community nursing services	Qualitative interviews with community nursing services patients	13 patients. Included patients with cancer, and receiving palliative care – unclear how many.	Three main categories: relationship with the nurse, care process and being able to stay out of hospital. Relationship: all reported on importance of relationship with nurse. Need to have rapport and feel comfortable. Communication important. Relationship developed over time.
Wilson (1999).	To evaluate care given by DNs as	Semi-structured interview, incorporating	14 carers (100% of those approached).	Accessibility and availability: Praised.

Author, Date, Country	Research question/ theme	Research approach	Participants	Findings/outcomes
UK	perceived by carers who have looked after a family member at home during terminal stages of cancer	STAS. Purposive sample of those on DN caseload.		Interpersonal relationships: appreciative of support and advice, friendly, humorous. Kind. Communication skills: taking time, listening, keeping informed. Giving information. Death at home important.
Wright (2002) UK	To explore the role of the district nurse in caring for dying people.	Qualitative semi- structured interviews with vignettes	6 DNs from one community trust.	Importance of relationship between DN and clients and family – fundamental in shaping the approach to care.

Table 2. Summary details of included studies.