

The role of UK district nurses in providing care for adult patients with a terminal diagnosis: a meta-ethnography

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Abstract

Aim: To explore the role of UK district nurses in providing care for adult patients with a terminal diagnosis by reviewing qualitative research. **Design:** Meta-ethnography was used to conduct the synthesis. **Data sources:** CINAHL, MEDLINE and British Nursing Index (BNI) were searched comprehensively for primary research relating to the role of UK district nurses in palliative care. **Review methods:** The abstracts and titles of 700 papers were screened against inclusion criteria, of these 97 full papers were appraised. Some 24 studies reported in 25 papers were selected for inclusion in the synthesis. **Findings:** In total, five key themes were identified: valuing the role; practical role; relationships with patients and families; providing psychological support; and role uncertainty. Further synthesis yielded two 'lines of argument'. The concept of the 'expert friend' argues that the atypical relationship district nurses cultivate with patients underpins district nurses' provision of palliative care and profoundly influences the nature of psychological support given. Secondly, the concept of 'threat and opportunity' encapsulates the threat district nurses can feel to their traditional role in palliative care through changing health and social policy, while recognising the benefits that access to specialist knowledge and better training can bring. **Conclusion:** The findings have implications for understanding the motivators and barriers experienced by district nurses delivering palliative care in a time of unprecedented change to community health services.

Key words: Palliative care ● District nurse ● Meta-ethnography ● Community health nursing

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2009). However, the 20th century saw an insidious migration of health care from community to hospital. Along with the medical treatment of illness came the medicalisation of death itself (Smith, 2000; Kellehear, 2007). Dying patients were removed from home and family, to die a modern death in the new NHS (Clark, 2002). Illich (1976) and others began to suggest that the medical profession had overreached itself. Many would now argue that death should be reclaimed as a natural stage of life, and that prolonging life (or perhaps prolonging death) with the latest medical advances, may be neither dignified nor acceptable to patients and relatives. The statistics would support this view; of those that expressed a preference, 81% of UK patients in 2012 would have preferred to die at home, while the majority actually died in hospital (Office of National Statistics, 2014).

After 20 years of decline in the UK (Department of Health (DH), 2008), death rates are now expected to increase year on year. With the government's continuing strategy to support patients in their choice to die at home (DoH, 2008), and the latest evidence that rates of home death are now increasing (Gomes et al, 2012; Gao et al, 2013), demand for palliative care services in the community is likely to be ever greater. With the growth of specialist palliative care services within the community, it is vital that UK DNs have a clear understanding of the service they provide, and are positioned to adapt to evolving practice in palliative care if they wish to retain the key position that they have historically occupied.

Throughout this study, the term 'DN' has been used to encompass the role of both those UK nurses with the specialist district nursing qualification, and those registered community nurses working as part of a UK district nursing team.

Aim

To explore the role of UK DNs in providing care for adult patients with a terminal diagnosis by reviewing qualitative research.

Palliative care has been fundamental to district nurses (DNs) ever since William Rathbone first employed a nurse to look after his dying wife in 1859 (Toofany, 2007). After his wife's death, he retained her services and sent her (and subsequently other nurses) out into the 'districts' of Liverpool to tend to the health of the poor (Queens Nursing Institute, 2013). From this was born district nursing. At that time, and for many years afterwards, the majority of people died in their own homes, and DNs, who had provided care throughout patients' lives remained central to providing care in their final days of life (Pellet,

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Methods

Study design

Simple summaries of literature lack the power of synthesis to combine data from studies to uncover new understanding. This study used a meta-ethnography approach, an established method of synthesising qualitative research (not just ethnographies), in order to seek higher order interpretations that explain why DNs exhibit the attitudes and behaviours that have been studied. Meta-ethnography is a highly interpretive and inductive method, which utilises ‘lines-of-argument’ (Noblit and Hare, 1988) that can provide new conceptual insights, not always evident from (but consistent with) the individual studies.

Search methods

In September 2013, CINAHL, British Nursing Index (BNI) and MEDLINE were searched using the following terms: (palliative OR terminal* OR dying OR ‘end of life’) AND (district nurs* OR community nurs*)

Inclusion criteria

Inclusion criteria were developed and article titles and abstracts initially screened. As this review was concerned with the role of UK DNs in the context of a changing UK policy agenda, any research dealing with non-UK DNs (or their patients or carers) was excluded. Thus many studies from the USA, Scandinavia, Canada and Australia were omitted, revealing a relative paucity of high-quality UK research on this theme. Only studies of peer-reviewed primary qualitative research were considered. In addition, articles had to relate to the role of the DN in palliative care with adult patients. The utility of each study became evident as data were extracted, and no studies were omitted on quality grounds.

Search outcome

The searches found 697 papers after removing duplicates. In addition, 3 papers were identified by key author searching and reference list searches. Some 603 papers were excluded by screening of abstracts against the inclusion criteria. After reviewing the methods and results sections of the remaining 97 full-text papers, 25 papers covering 24 studies were identified for inclusion (Figure 1).

Data abstraction

The data from the studies was extracted and coded in an excel spreadsheet. The objective of coding was to ensure the concepts in the studies were captured clearly and concisely. Codes could

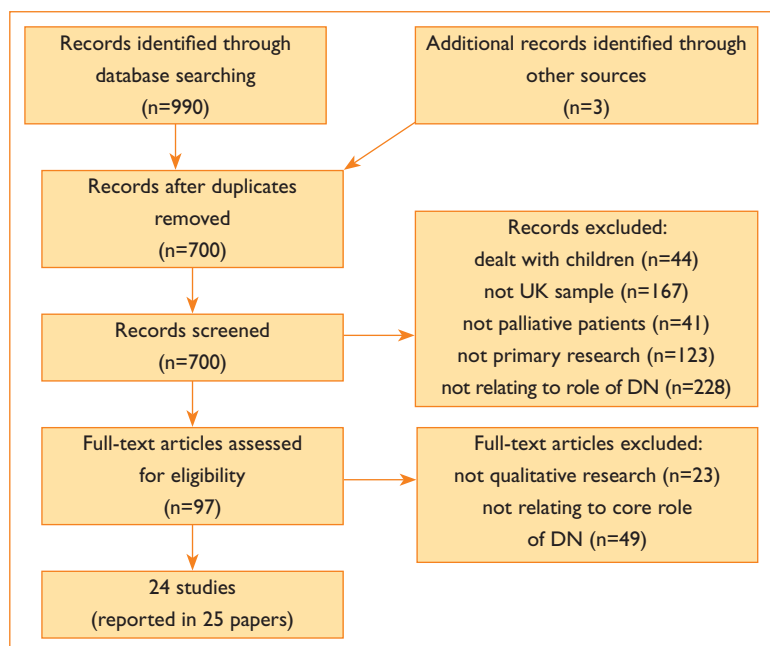


Figure 1. Flow diagram of study inclusion

be short extracts from the study or a paraphrase of a section of text. An example code from Law (2009) was ‘DN may refuse to visit without a physical need’. In total, 268 codes were identified.

Data synthesis: study characteristics

One study used a retrospective questionnaire; the remainder utilised focus groups and/or interviews, with 6 studies also incorporating an observational component. Only 9 studies involved patients or carers; the remainder investigated the opinions of DNs. Some 650 UK DNs were represented in the studies, the majority using very small samples from the researcher’s local health setting.

Using the meta-ethnographic approach

In practical terms, Noblit and Hare (1988) suggested 7 steps to the synthesis. Steps four through to six encapsulate the unique approach of meta-ethnography (Box 1).

In order to reduce the complexity, the codes were arranged into five themes chosen to group the data into congruent categories (Table 3):

- Valuing the role
- Practical role
- Relationships with patients and families
- Providing psychological support
- Role uncertainty.

Grouping the codes enabled comparisons to be made, and translations performed between the studies within each theme. Thus the five themes became the basis for ‘reciprocal translations’ between the papers (Noblitt and Hare, 1988).

Box 1. Phases of meta-ethnography
(Noblit and Hare, 1988)

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis

Results

Valuing the role

DNs placed a high value on palliative care, describing the work as a privilege (Griffiths, 1997; Goodman et al, 1998; Austin et al, 2000; Burt et al, 2008; Griffiths et al, 2013). DNs viewed palliative care as ‘real nursing’ and enjoyed feeling they were ‘making a difference’, although the work could be stressful (Seale, 1992; Andrew and Whyte, 2004; Dunne et al, 2005; Griffiths et al, 2007):

‘It’s part of the job I really enjoy. I get a lot of satisfaction from it. I think it’s because we are getting closer to people and building relationships and hoping you’ve helped ...’(DN in Andrew and Whyte, 2004)

King et al (2010) suggested that palliative care was inherently congruent with district nursing, allowing holistic care to patients and families at a critical point in their lives. Organisational change had gradually eroded this holistic approach, but DNs remained dedicated to their role in providing palliative care (Burt et al, 2008; King et al, 2010). Balancing palliative care with a generalist workload created stresses (Burt et al, 2008), and DNs often prioritised the physical tasks over supportive ones when time was short (Luker et al, 2000).

Practical role

DNs provided practical support to patients, in the form of undertaking physical, informational and organisational tasks. Most DN visits had a physical focus (Griffiths et al, 2013), including providing personal cares associated with advanced disease, discussing activities of daily living, managing symptoms and medication and ordering equipment (Austin et al, 2000; Wright, 2002; Andrew and Wright, 2004; Brown et al, 2011; Griffiths et al, 2013). DNs saw physical tasks as a means to perform a fuller assessment of the patient, and as an opportunity to build relationships (Luker et al, 2000; 2003; Griffiths et al, 2013).

Informational tasks included educating

patients and families, and sensitively translating medical information in an appropriate way for the patients’ and families’ needs (Wright, 2002; Andrew and Whyte, 2004; Brown et al, 2011).

DNs clearly took pride in their perceived role as coordinators of care, seeing themselves as gatekeepers to other services (Goodman, 1998; Austin et al, 2000; McIlfatrick and Curran, 2000; McHugh et al, 2003; Kennedy, 2005; Burt et al, 2008; King et al, 2010):

‘I think district nurses are at the top of the tree, without her, you know, the whole world would collapse ... Now without the DN you really would be struggling because there is not anyone else who would pull it all together.’ (DN in King et al, 2010)

Relationship with patients and families

Almost all the studies highlighted the centrality of the DN’s relationships with patients and their families. Luker et al (2000) stated that the relationship with the patient was the ‘essence’ of district nursing, while Wright (2002) argued that the relationship was the medium through which all care was given.

DNs always favoured early referral in order to establish a relationship of trust with patient and family (Seale, 1992; Griffiths, 1997; Goodman, 1998; Luker et al, 2000; Andrew and Whyte, 2004; Austin et al, 2000; McIlfatrick and Curran, 2000; McHugh et al, 2003; Dunne et al, 2005; Kennedy, 2005; Griffiths et al, 2007; Tomison and McDowell, 2011):

‘I like to get to know them while they are reasonably well really and build up a relationship then with them. And when they do become terminally ill they tend to accept more and trust you ...’ (DN in Austin et al, 2000)

Early visits to patients and families were therefore focused on building relationships and befriending the patient by chatting about everyday issues to create a rapport (Griffiths, 1997; Austin et al, 2000; Dunne et al, 2005; Griffiths et al, 2007; 2010; 2013).

‘I get on with them really well actually ... you know, they just sit there and ask me what I’ve been up to and, you know, just talk about everyday things.’ (DN in Griffiths et al, 2007)

DNs clearly expressed their desire to support families as well as patients, recognising their emotional needs and the crucial role they held (Seale, 1992; Goodman et al, 1998; Austin et al,

2000; Dunne et al, 2005; Kennedy, 2005; Griffiths et al, 2013; Minto and Strickland, 2011; Tomison and McDowell, 2011). Patients and families relied on the DN, appreciated a trusting relationship with them, and often felt affection towards them (Austin et al, 2000; Burt et al, 2000; Brown et al, 2011; Griffiths et al, 2013; Nagington et al, 2013):

‘They’re not strangers, you feel like you have known them for years.’ (Patient in Brown et al, 2011)

Relationships were characterised by an equality and reciprocity that patients felt contrasted with hospital nurses, and DNs were seen to make specific efforts to minimise power differentials with patients (Brown et al, 2011; Griffiths et al, 2010; 2013). Some studies suggested that the DN relationship could go beyond the professional and become close to friendship:

‘No, they remain district nurses, but kind of friends ...’ (Patient in Nagington et al, 2013)

‘When you’re a district nurse and you get involved in palliative care, sometimes you get that you become part of the family and they rely on you and you know if they’ve become friends ...’ (DN in Austin et al, 2000)

Providing psychological support

The concept of therapeutic presence was evident in many studies (Luker et al, 2000; Wright, 2002; Andrew and Whyte, 2004; Griffiths et al, 2010; Brown et al, 2011; Tomison and McDowell, 2011; Griffiths et al, 2012). However, DNs had difficulty articulating the content of support visits, and worried that such visits lacked legitimacy as a nursing intervention:

‘... it’s not really been actually nursing care as such, it’s really been support I suppose as much as anything.’ (DN in Griffiths et al, 2007)

DNs felt they supported patients by visiting regularly to ‘keep an eye’ on things (Griffiths, 1997; Luker et al, 2003; Kennedy, 2005). Patients valued and enjoyed these visits but did not necessarily feel emotionally supported by them (Griffiths et al, 2010). DNs were experienced at dealing with palliative patients (Law, 2009), but nevertheless were uncomfortable talking about dying (Dunne et al, 2005; Munday et al, 2009) and used an informal conversational approach in support visits, described by Griffiths et al. (2007;

Table 3. Formation of translations

Reciprocal translation	Number of contributing papers	Number of contributing codes	Contributes to line of argument	
			The expert friend	Threat and opportunity
Valuing the role	10	23		*
Practical role	14	30	*	
Relationship with patient and families	22	64	*	*
Providing psychological support	23	81	*	
Role uncertainty	18	70		*

2010) as ‘chatting’. DNs frequently used gentle humour in their encounters; making the patient smile or laugh being seen as diverting them from the sick role (Law, 2009; Brown et al, 2011; Griffiths et al, 2013). Patients acknowledged the skill of the DN in eliciting information using their informal approach:

‘There’s ways of getting people to talk, isn’t there? To open up to you ... She has the right approach ... if (DN) comes in and says, “hi how are you? Oh, are you having breakfast ...” and she starts talking, and while she’s talking she’s asking me questions, but I’m not aware how deep the questions are until she’s gone, and then I think, God, that was clever.’ (Patient in Griffiths et al, 2013)

DNs’ descriptions of how they dealt with psychological issues varied with observed interactions and patients’ own perceptions of the visits (Griffiths et al, 2010). DNs felt they used ‘chatting’ to assess psychological needs, but observation revealed blocking tactics used by DNs to avoid dealing with patients’ emotional distress. The most common reaction was for the DN to simply change the subject:

‘DN: So how will you feel if you don’t actually go?’

Patient: Upset

DN: You feel, you feel that’s something you need to do? [Patient is upset and starts to cry]

DN: So, moving swiftly on....’ (Griffiths et al, 2010)

Role uncertainty

DNs felt that the care they gave was ‘invisible’ to rest of the health-care team (Goodman et al, 1998; Luker et al, 2000), and DN managers were

‘The traditional relationship that DNs cultivate with their patients, often close to friendship, underpins all aspects of palliative care delivery...’

unaware of the impact of palliative care on DNs:

‘I just think it goes wholly unrecognised. I really do!... But nobody higher up acknowledges now the percentage of our workload this takes. And the emotional impact.’ (DN in focus group in Burt et al, 2008)

Despite DNs’ long history of undertaking support visits for palliative patients, many GPs and acute services thought that DNs only visited to give physical care (Austin et al, 2000; McHugh et al, 2003).

Lack of information provided by secondary care could leave DNs feeling isolated and disenfranchised (Seale, 1992; McIlfratrick and Curran, 2000; Andrew and Whyte, 2004):

‘You get half the jigsaw, we’re told very minimal information.’ (DN in McHugh et al, 2003)

Poor knowledge of policy developments in palliative care such as the Gold Standard Framework (GSF) (GSF, 2013) contributed to a reactive approach to identifying patients in the last year of life. There was, however, some recognition of the need for a more proactive service:

‘I mean, I think probably resources have to shift or, you know, our role has to kind of develop and change along those lines because at the moment it is still a very reactive service.’ (DN in Tomison and McDowell, 2011)’

Some DNs felt their position was threatened by specialists who were seen as above them in the hierarchy, and feared being edged out of the role they had traditionally occupied, leading to a defensive response (Burt et al, 2008; King et al, 2010):

‘I have got that experience and I’ve got the knowledge behind it and the professional judgment...but I think the view with some agencies is that we don’t have the ability, or we shouldn’t really have the right to do something, because it’s treading on their toes.’ (DN in Burt et al, 2008)

Nevertheless, DNs often welcomed access to Macmillan nurses for giving psychological support and for their expertise:

‘... the Macmillan service, I use them an awful lot, I find them invaluable ... I would use them for advice and support for myself and for the families.’ (DN in Austin et al, 2000)

While some DNs saw a return to ‘hands-on’ nursing care as one of the rewarding areas of nursing the dying, others felt that even in palliative care this role had been lost (Griffiths, 1997; Austin et al, 2000; Griffiths et al, 2007):

I used to say it’s one of the very few fields that you could have holistic care, true holistic care. I don’t feel like that now ... well you know, getting up, having a wash and getting dressed in the morning isn’t the nurse’s job so that goes over to social services. I feel that’s not a good step.’ (DN in Austin et al, 2000)

Some DNs doubted they had the skills to give psychological support or if this was even part of their role (Griffiths, 1997; McIlfratrick and Curran, 2000; Kennedy, 2005; Griffiths et al, 2007; 2010). Consequently, they readily devolved responsibility to the Macmillan nurse:

‘If I know [Macmillan Nurse] is going in, as she does, she deals with these sort of personal, erm, the more counseling side of things much more, she’s very good at that. We tend to do strictly procedural things you know ...’ (DN in Griffiths et al, 2007)

Lines of argument

The synthesis of translations (Noblitt and Hare, 1988) was performed by comparing the five reciprocal translations above to identify ‘lines of argument’ that linked the themes so as to gain new understanding.

The expert friend

A line of argument was traced between the reciprocal translations of ‘practical role’, ‘relationships with patients and families’ and ‘providing psychological support’ which may aid the understanding of the motivators and behaviour of DNs. The traditional relationship that DNs cultivate with their patients, often close to friendship, underpins all aspects of palliative care delivery, profoundly influencing how DNs give psychological support. The term ‘expert friend’ has been used to describe this concept. The DN relationship uses chatting, humour, and a sense of normalcy to perform assessments and provide support. The expert friend:

- Knows the patient very well
- Minimises power differentials
- Provides a bridge between home and hospital
- Brings reassurance, maintains roles and a sense of normality
- Is available and will try to help
- Accesses other resources and services.

DNs value this relationship, but feel that its worth is not well acknowledged by other health professionals. They fear that overt attempts at psychological support would introduce a power differential, distancing the patient, and that they will instead become the ‘friendly expert’ common in clinician-patient interactions. DNs value their unique relationship with patients and are resistant to pressures to change.

Threat and opportunity

A second line of argument, ‘threat and opportunity’, could be traced between the reciprocal translations for ‘valuing the role’, ‘relationships with patient and families’ and ‘role uncertainty’. Palliative care is prized for being holistic care, congruent with the ideals of district nursing, but DNs have seen the role eroded by the separation of health and social care, and the emergence of specialist palliative care services. Some DNs feel their skills and traditional relationship with the patient are threatened by a changing health system. However, DNs also acknowledge that good teamwork and communication are prerequisites for high-quality palliative care, and value access to specialist knowledge. They perceive the need to adapt to new ways of working in order to maintain their role as the linchpin of palliative care in the home, but are hindered by insufficient training, leading to reduced confidence.

Discussion

This review has synthesised data from the included studies, generating two lines of argument that offer theoretical insights into the practice and behaviour of DNs working with palliative patients.

It was clear from the body of evidence that the relationship with patients and families was at the very core of district nursing, and even visits with a physical focus were seen as an opportunity for building relationships. There appeared to be elements of the DN relationship that distinguished it from that of other health professionals. Often patients and families were well known to DNs before palliation, and DNs were able to give continuity of care lasting to death and bereavement care. DNs specifically minimised power differentials and used an informal, chatting style which was near to friendship. Observational studies by Griffiths et al (2007; 2010) provided compelling evidence that DNs, while highly skilled at assessing patients’ and families’ needs through their informal approach, specifically avoided overt end-of-life discussions. DNs used avoidance tactics such as changing the subject when faced with patients’ emotional pain. This may be explained

by DNs’ discomfort in talking about dying (Dunne et al, 2005; Munday et al, 2009), lack of confidence and skills in such discussions (Griffiths 1997; 2007; 2010; McIlpatrick and Curran, 2000; Kennedy, 2005) and a belief that the DN role is primarily for physical tasks (Austin et al, 2003; Luker et al, 2003; McHugh et al, 2003; Law, 2009). However, it would seem that elements of this relationship, so clearly valued by DNs, with its focus on maintaining normalcy, and minimising power differentials may obstruct delivery of psychological support. The studies demonstrated that both patients and DNs were aware that difficult topics were often avoided, but nevertheless valued the friendly, everyday relationships they mutually nurtured. Interestingly, early studies (Grande et al, 1996; McIlpatrick and Curran, 2000) had found ‘kindness’ to be the most valued aspect of palliative care (an attribute not mentioned in more recent studies). DNs may feel that kindness in their relationships provides psychological benefits to patients while avoiding the difficulties of emotionally-charged conversations. Additional training in end-of-life communication skills may be ineffective without appreciation of the conviction DNs have in their current approach which largely avoids tackling patients’ emotional distress head on.

A recurrent theme throughout the studies was DNs’ desire to have patients referred early, to allow time to build relationships and anticipate problems. This anticipatory aspect is in keeping with the principles of the end of life strategy (DH, 2008) and GSF (2013), promoting a proactive approach to identifying and assessing patients who may be in the last year of life, although DNs often lacked knowledge of these policy initiatives.

Translating information into an appropriate level for the patient and family was seen as part of the role, but DNs felt that they were not always ‘in the loop’ themselves regarding such information, and that their full role was not recognised by others. DNs saw themselves as the organisers of care and the gateway to other services, yet simultaneously felt disenfranchised from the wider health team. Poor information from the secondary care team was a persistent theme throughout the timescale of this review; indeed Seale (1992) indicated there had only been a slight improvement since an earlier study in 1969 (Cartwright et al, 1973).

The studies universally demonstrated that DNs greatly valued palliative care, and this was explained in terms of its congruence with the values of the DN service in providing holistic care to

‘A recurrent theme throughout the studies was DNs’ desire to have patients referred early, to allow time to build relationships and anticipate problems.’

Box 2. Recommendations for practice

Implications for practice and policy:

- Education alone may be ineffective at encouraging district nurses (DNs) to engage with patients' need for psychological support.
- Understanding the perceived threat to a role highly valued by DNs will help allay fears over organizational change.
- DNs are poorly informed of recent policy initiatives and emerging areas of palliative care provision.
- DNs' referral criteria should encourage early referral of palliative patients even where there is no physical need.
- Flow of information between secondary care and DNs should be encouraged.

patients and families at a critical time. Goodman et al (1998) additionally highlighted this as an area where DNs felt they gained kudos as the leaders of care, and GPs acknowledged their expertise. This could lead to DNs becoming possessive of palliative patients (Griffiths, 1997). The evidence regarding protectionist attitudes among DNs was mixed. Both Burt et al (2008) and King et al (2010) found resentment of specialist palliative nurses' encroachment on DNs' established role, and a perception that DNs' end-of-life skills were considered subordinate to those of specialist nurses. Conversely, Bergen (1992) found no such attitudes in her study. DNs in several studies emphasised the benefits of teamwork, and appreciated specialist nurses as a source of advice (Austin et al, 2000; McIlfatrick and Curran, 2000; Tomison and McDowell, 2011), readily devolving responsibility for psychological support to them (Griffiths et al, 2007). DNs also regretted the erosion of their holistic role since the division of health and social care, although some DNs felt that palliative care still legitimised the provision of basic care.

It was notable that when considering the studies chronologically from 1992 to 2013, no pattern emerged showing a significant change in the issues raised by this synthesis; it was evident that the traditional DN to palliative patient relationship has remained remarkably resilient to change in a turbulent health system over the last 2 decades.

Further research identified

This study has highlighted several areas requiring further research. There is an over-reliance on DNs' views of their role; further observational research and studies representing the views of the patient and family would redress this imbalance. Studies pertaining to emerging aspects of palliative care such as advance care planning, spirituality, dementia and bereavement support by DNs are largely absent from UK research, and studies are biased towards patients with cancer. This may indicate that these areas are under researched or are not being currently addressed


in practice in the UK. Finally, no studies were found that look at the outcomes of palliative care undertaken by DNs.

Limitations

As sole author, bias may have been introduced in judgments on inclusion of studies and data extraction. Specialist software was not used in the coding stage of this review. Mainly purposive and self-selecting selection criteria within the studies, and small sample sizes are likely to have biased the results towards DNs with an active interest in palliative care, and it is probable that some less positive attitudes may have emerged had randomised sampling been used. Finally, the studies mainly related to cancer patients, and were restricted to the UK.

Conclusion

Meta-ethnography allowed new interpretations of the body of research on the role of DNs in palliative care. The approach tends to use fewer studies than other methods, and this allows in-depth interpretation of the included papers.

In addition to five reciprocal translations that combined data from contributing papers into congruent topics, the process yielded two main findings. The concepts of the 'expert friend', and 'threat and opportunity' have clinical implications for practice (Box 2), and provide a theoretical underpinning to the introduction of this paper, which describes the historic position of DNs in delivering palliative care, and the uncertainty created by a changing and uncertain policy context. 

To see full details of the studies included in this study, please contact the editor.

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Declaration of interests

The authors have no conflicts of interest to declare.

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