

Aims, actions and advance care planning by district nurses providing palliative care: an ethnographic observational study

Abstract

Background: District nurses are core providers of palliative care, yet little is known about the way that they provide care to people at home.

Aims: To investigate the role and practice of the district nurse in palliative care provision.

Methods: Ethnographic study, with non-participant observation of district nurse-palliative care patient encounters, and post observation interviews. District nurse teams from three geographical areas in North West England participated. Data were analysed iteratively, facilitated through use of NVivo, using techniques of constant comparison.

Findings: Seventeen encounters were observed, with 23 post observation interviews (11 district nurse, 12 patient/carer). Core themes were 'planning for the future' and 'caring in the moment'. District nurses described how they provided and planned future care, but observations showed care 'in the moment' focused on physical symptom management.

Conclusion: District nurses facilitate friendly relationship building which allows detailed management of current symptomatology, but with little evidence of advance care planning.

Keywords: District nurse; community nurse; palliative care; ethnography; observation.

Key points

- District nurses are key providers of palliative care at home, but little is known about how they enact their role.
- Observational research is important to understand what is done, not only what people say they do.
- District nurses talked about relationship building to enable excellent future care.
- Observed care showed familiarity with patients facilitating management of physical symptoms, but little advance care planning in practice.
- District nurses may struggle with discussing future care, potentially because of an information gap about prognosis, or requiring key skills to start and complete such conversations within working constraints.

Reflective questions

- a) What do people consider to be the main barriers to district nurses providing excellent palliative care at home?
- b) What could or should the role of the district nurse be in providing contemporary palliative care at home?
- c) What educational preparation might district nurses need to enable them to extend their skills?

Background:

Palliative care is provided to those who have life-threatening illness, and can be offered from early in the course of an illness through to death and bereavement (Sepúlveda et al., 2002). Palliative care is offered in a range of settings, but it is clear that home care, and possibly death at home, is preferred by most patients (Gomes et al., 2012, Higginson and Sen-Gupta, 2000). These preferences are reflected many countries health policies, which emphasise providing care close to home at the end of life (Australia, 2010, Health, 2008, Meier, 2011), and there is evidence that palliative home care is cost effective (Bosanquet, 2002, Care, 2012, Hatzianreou et al., 2008). Enacting such policies affects care processes and outcomes: home care or contact with a palliative care team appears associated with home death (Alonso-Babarro et al., 2012, Bell et al., 2010, Brogaard et al., 2012, Cohen et al., 2010), and there is a shift to home death in many countries (Gomes et al., 2012).

Whilst evidence suggests that palliative home care is needed and beneficial, less is known about the best way to provide such care. Most available evidence focuses on specialist palliative care providers, often in in-patient settings (Gaertner et al., 2017, Higginson and Evans, 2010, Kavalieratos et al., 2016, Zimmermann et al., 2008), less is known about generalists such as general practitioners and community nurses despite their core role in care provision in many health care systems. Whilst there are policy initiatives aimed at improving palliative care provided in home and community settings, such as the Gold Standards Framework, there is remarkably little evidence of the effectiveness of such programmes (Shaw et al., 2010, Walshe et al., 2008). Understanding the role of generalist palliative care providers when developing appropriate care models is recognised as critical (Shipman et al., 2008).

Our review of the role of generalist community nurses (district nurses) in the provision of palliative care reveals much research in the area investigating nurses perceptions (Walshe and Luker, 2010). Nurses report valuing providing palliative care and work to develop a relationship with patients. They feel they have key skills in physical care provision, but that their role is undervalued. We clearly

understand nurses stated care aims and their own descriptions of care given. However, there is little detailed knowledge about the actions of nurses. Few studies observe community (district) nurses providing palliative care, and how such care develops over time (Griffiths et al., 2013, Griffiths et al., 2010, Kennedy, 2005, Law, 1997, McKenzie et al., 2007). This poor understanding of care processes can hamper efforts to influence care outcomes. There is a need for rigorous longitudinal research, following district nurse encounters with patients throughout the palliative phase of their illness to understand the role and practice of the district nurse and how this may change according to the needs and circumstances of the patients.

Methods

The aim of this study was to investigate the role of the district nurse in palliative care provision, with a particular focus on observational exploration of their role and practice in providing patient care. The study was designed to answer the questions:

- a. How, why and when do district nurses provide palliative care to patients?
- b. What is the nature and content of district nurse palliative care provision?

This was designed to provide an understanding of how district nurses enact their role with palliative care patients, focusing on the issues they address, and the care they provide, during their visits to patients from the early supportive phase through to death or discharge.

Design

This study used an ethnographic approach, and in line with contemporary ethnographic thinking, a multi-site, multi-voice approach was taken, giving equal accord to practitioners, patients (and their carers) of the district nursing services studied (Hammersley and Atkinson, 2007, Marcus, 1998). Non-participant observation of district nurse/palliative care patient encounters was the principal data

collection method, together with post observation interviews with those observed. Qualitative observational data collection methods can contribute to theoretical and conceptual development and the explanation of social processes, and care structures in palliative care (Walshe et al., 2011).

Sampling

There is little evidence to guide sampling of either patients or district nursing teams, nor obvious sampling frame from which to choose. There were therefore three aspects to sampling for this study: the geographical areas, the district nursing teams within these areas, and the palliative care patients receiving care from these teams.

- a) Primary care providing organisations from North West England were arbitrarily selected to maximise variability with regard to the demography of the population they serve (urban/rural, ethnicity, deprivation indices). Initial visits were made to group meetings of district nurses within these areas to introduce the study.
- b) Lists of district nurse teams were obtained from each primary care organisation. For the smaller areas, each team was invited to participate. For the larger areas district nurse teams were selected arbitrarily from lists stratified by team size and the size of the population they served.
- c) Patients (and subsequently their nominated family carers) that met the inclusion criteria were purposively invited to participate by the participating district nurse teams.

Selection and exclusion criteria:

District nurse participant inclusion criteria: All district nurse team leaders working within participating primary care organisations. All district nurse team members working with recruited district nurse team leaders.

Patient participant inclusion criteria:	All adult (over 18) patients in the palliative phase of their illness currently cared for by a recruited district nurse team member. No upper age limit. Competent to consent to participate as judged by any registered health care professionals providing care to them.
Informal carer participant inclusion criteria:	All adult (over 18) informal/family carers of recruited patients. No upper age limit.
District nurse participant exclusion criteria:	No exclusion criteria.
Patient participant exclusion criteria:	Patients on district nursing caseloads not in the palliative phase of any illness. Patients judged not competent to consent to participate by any registered health care professional providing care to them.
Carer participants exclusion criteria:	Those providing paid care to the participant.

For the purpose of this study palliative care was taken to mean care given when death might reasonably be expected within a year. The term district nurses was taken to mean both team leaders who hold a specialist practitioner qualification in district nursing, but also the registered nurses and health care assistants who work within their teams.

Recruitment

Potential district nurse team leader participants (those identified by the primary care organisation as managers of locality-based district nursing teams). were invited to participate by means of a letter of invitation, which also contained an information sheet about the study, reply slip and stamped addressed envelope. They indicated on the reply slip whether or not they were interested in

participating in the study. If there was no reply within 2-3 weeks then reminders were sent. Once the district nurse team leader agreed to participate, the members of their district nursing team were approached to participate in the research.

Potential patient participants were identified by participating district nursing teams. District nursing teams were asked to identify patients (ideally recently referred to their care) who meet the inclusion criteria. Participating teams were asked to identify two or three potential patient participants. Teams were supplied with patient recruitment packs to give to potential patients (information sheet, reply slip and SAE). Patients were recruited to the study if they returned the reply slip to the researcher indicating that they are interested in taking part in the study. Potential carer participants were identified by participating patients and received similar information to the patient and responded in the same way. Nurses, patients and carers gave written consent to participate in the study

Frequent communication with participating teams was used to encourage patient/carers recruitment, with the aim of ceasing recruitment when data saturation was achieved.

Data collection:

Data collection took place between March 2009 and March 2011. Non-participant observation of the home visits to and subsequent interactions between patients, carers and district nurses, and the care given and received formed the core data collection method. In-depth separate interviews with patients/carers and district nurses followed the observation, to explore understandings of observational data. Data were gathered where possible longitudinally (up to 3 observations per recruited patient), to observe and understand how care changes over time and with alterations to patients' and carers' needs. Observation intervals were determined after discussion with district nurses and patients. Observations and interviews were, with permission, audio-recorded. Observation was conducted by CW, a trained district nurse, although at the point of data collection had not been in direct district nursing practice for ten years. Free text detailed field notes were used to capture the

activities observed including a sketch map of the location, and time-stamped (to match audio-recordings) notes about movements and reactions. Additional field notes and reflections were captured in free text after the observations and interviews. Observations were sensitively conducted to minimise impact on the district nurse/patient encounter, with careful attention to nurse, patient and carer cues to cease observations (Walshe et al., 2011).

Data analysis

Data analysis took place iteratively throughout the study, and informed the further conduct of the study and recruitment of participants. Audio-recordings of observations and interview data were fully transcribed and data managed using NVivo™. Analysis followed accepted ethnographic principles (Hammersley and Atkinson, 2007). Initially, analytical concepts and categories were developed from familiarisation with the data (verbatim transcripts of observed encounters, field notes, and interview transcripts) and with reference to existing theory and literature. Techniques of constant comparison were used to generate concepts and typologies of concepts from the data. Anonymised data from core themes were shared with a research advisory group (including users) to aid interpretation.

Ethical considerations

Non-participant observation raises particular ethical issues around consent, privacy, confidentiality, and the potential to observe poor care (Walshe et al., 2011). These were addressed by paying attention to involving health care professionals in negotiating access to participants, obtaining written informed consent from all professional, patient and carer participants, but also using the concept of process consent where consent was renegotiated at different stages of the interactions, and verbally recorded. Care has been taken to avoid sufficient detail being given to allow identification of the primary care trust, nursing staff, patients or carers, and the assigning of alphanumeric codes to participants. No issues of sub-optimal care were observed, but a clear protocol was developed to address this if required. If participants became distressed at all during the observation(s) or interviews

a clear distress protocol was followed, one observation was not commenced due to severe deterioration in the patient’s condition. NHS research ethics committee (08/H1003/130) and NHS R&D approvals were sought and given and all research governance requirements followed.

Findings

Twelve teams of district nurses agreed to participate in the research across three geographical areas. Patient recruitment proved challenging due to issues such as staff shortages, and not all teams recruited patients to the study, thus data are given here on those patient/nurse dyads observed. Table 1 displays summary data about those recruited for whom observational/interview data were collected. District nurses did not collect data on those invited to participate but who declined.

Table 1. Study participants

District nurses	Participants (n=8)
Qualifications	District Nurse Specialist Practitioner Qualification (n=6) RGN (n=8)
Training in palliative care	Study days/short courses (n=5)
Years’ experience in district nursing	Range 2 – 26 years
Gender	F (n=7), M (n=1)
Patients	Participants (n=11)
Diagnosis	All participants had a cancer diagnosis. Mesothelioma, Lymphoma, Oesophagus, Ovary (n=2), Colo-rectal (n=2), Melanoma, Lung, Breast (n=2)
Gender	F (n=6), M (n=5)
Age	Range from 52 years – 84 years.
Prognosis	Died during the study period (n=7)

Seventeen district nursing/patient encounters were observed (mean length 31 mins, range 15-64), with 23 post observation interviews (11 district nursing (mean length 19 mins, range 13-37), 12 patient/carer (mean length 28 mins, range 16-39). Some planned future observations were not able to be conducted because of deterioration/death of the patient, or transfer to another care setting (Hospital, Hospice or Nursing Home). Timing and availability issues also affected the collection of some post-observation interview data.

The two core themes determined from these data were 'planning for the future' and 'caring in the moment'. 'Planning for the future' encapsulates the district nurses views of their overall care aims and objectives, and 'caring in the moment' reflects the realities of the observed care given and the immediate visit aims, although both themes draw from all data collected. Data extracts are identified by geographical area (A, B, C), whether district nurse (DN), community staff nurse (SN) or patient (P), and if interview or observation, and which in the series if multiple observations and interviews conducted.

PLANNING FOR THE FUTURE

Building the relationship

District nurses reveal that they spend much time considering future care. They invest time and energy building relationships with patients to facilitate such future care and ongoing communication. Using the home visit to build a relationship with patients and other family members appears central to the way the district nurses construct their role in providing palliative care:

'And so I... it took me a little bit of time to feel that they were comfortable with me.

And I do feel that now and I feel it is a comfortable visit. And I feel that they probably actually look forward to us coming. And I feel that we have a good relationship and

that they would tell me if there were problems and they would ring up in between if there was problems.’ ADN1/P1/DNint1

The patient didn’t describe this in terms of a relationship, but described how they care and look after him:

Well they’re there to look after me. And, er...or if I’m in pain treat me, er, and they reassure me...an, and put me on some different tablets. They ask me how I’m getting on. ADN1/P1/Pint1

The purpose of such a relationship, to the nurse, was more than easy going friendship, but was perceived as part of their skilled assessment and care-giving. Nurses describe the way they interact with patients as ‘artistry’, capitalising on the privilege of home visiting to develop a nuanced understanding of the patient and their environment:

‘It’s your tool kit of interpersonal skills that you go into a situation and as well as reading the social context, responding to the physical need, you are reading the social context simultaneously and it’s almost a form of artistry, isn’t it, how you are doing that balancing, drawing upon your interpersonal skills and identifying with something that ‘oh, you like painting, oh I’ve always really been interested in painting’ and ‘oh have you’, and that’s the way it comes about, isn’t it, you pick one key aspect’.
BDN1/P2/DNint1

Deploying such interpersonal skills means that district nurses feel that they can provide immediate excellent care, but that care benefits from the depth that could be developed in relationships over time, and patients may be more receptive to care as a result.

Starting to think about the end of life

District nurses justify time spent building relationships because it was felt not only to facilitate immediate care, but to assist in planning for and providing care at the very end of life. Nurses acknowledge how difficult it can be to initiate conversations about advance care planning, but knowing the patient made this easier for them:

That's the key with any palliative because if you've not got that [relationship] it's very hard to have to go in and at that crucial time and start talking about death, where do you want to die, where do you want...do you know what I mean. I find it a strain whereas if I've built that relationship up it does...it becomes a natural progression that you will lead and sometimes they'll open up and say it. You don't have to ask the questions, they'll open up and tell it you. CDN3/P1/DNint1

Nurses feel they can use this relationship as a vehicle to allow patients to dictate the pace of planning, at a time of their choosing. However in the data extract above, there is acknowledgement that this can happen 'sometimes', initiated by patients, and there is a concern that this reactive approach may lead to care planning avoidance. Here, although nurses have been involved with a patient for over a year, it appears advance planning for the very end of life has not yet been discussed because they judge the patient 'not there':

'Because I know her so well and that's because I've been seeing her for over a year really. I'd be planning ahead, if she decided she wanted to die at home, I'd start looking at the drugs in the house, I'd start preparing her for it, I'd start getting more support in, getting some night sits, getting some Social Service input, just, you know, I'd start that remit, then, of planning, planning ahead but, she isn't there, at the moment'. BDN1 SR2/P3/DNint2

Nurses appear keen to be led by patients' cues but this may mean that only patients who are articulate and open to this approach engage in such planning with district nurses:

No. He's quite open, so he does discuss all of his problems, and so is his wife, and they, you know, over the few months all the nurses have got a rapport with him, so they do discuss problems when they come to it ... The thing is, though, because we're discussing a lot of things, so they need to know that they can trust us, and they need to know we'll be there for them, so it is good to be able to have a good rapport. And also for us to get the right information out of them. We don't want, you know, to be going in there as a stranger for them to then spill the heart out. So it is very important. BDN1SN1P1:

Awareness and 'being ready'

It appears more common for end of life care discussions to occur when the district nurse recognises that a patient is 'ready' to be involved in advance care planning, and concepts of 'readiness' and 'awareness' affect the ways that district nurses approach care. Awareness or acceptance of prognosis is critical:

'I'm not quite sure that her prognosis is as buoyant as... they both feel it is. Because it is slightly wrapped round her bowel. But at the moment we go with the positive to keep them positive... Because I just think if someone is optimistic you get through your treatment better...you're in a better frame of mind for each treatment, and I think if you start putting negatives in at this point, it can affect, how they are mentally. I kind of probably prefer not to know anyway and just go along the path with the patient on their journey really..' ADN1/SN1/P3/DNint2

Nurses report a desire to walk alongside patients on their journey, responding to the patient's emerging knowledge of the care situation and prognosis, and taking their cue in advance care planning from their interpretation of the patient's perception of prognosis or their perception of the patient's coping strategies:

So, she says, but, you know, but she's very in tune with her symptoms and what's going on and I think she knows a little bit, deep down, that that pain is probably cancer related. Did you hear her? She said, like, how she felt before was a little bit...so she probably knows, but I think she tries to, block...block it out really. That's why, I really, couldn't approach PPC [preferred priorities for care document] just yet, could you...can you see where I'm coming from? BDN1 SR2 P4 DN int 1:

Prognosis and planning

These district nurses worked outside the hospital systems, in primary care only organisations, and were not privy to information from other consultations or scan and blood test results. A common approach therefore was to have discussions with patients in response to the narrative imposed by patients' knowledge of disease progression as indicated by medical professionals:

BDN1: I think that very much depends on the outcome of the oncology review, because my feelings are that we will need to progress planning for end stage care really, and we've talked about it loosely in the past, but I think we need to move into that next level of service provision, which she has never avoided talking about, but really it's never been a big part of our conversations, because the need wasn't there at the time.

Anticipatory care is hampered by a lack of detailed information about patients' disease, treatment and prognosis, with information usually gained directly from the patients report rather than direct communication with other health care professionals:

Well, at that point I didn't know that they were going to be doing the follow up chemo. Um, she, she told me that they hadn't got all of the tumour cos there's problems during surgery, so I didn't know whether I was going into her that they were gonna be doing more chemo...or they were going to... You know, I might

have been going into this whole prognosis and they weren't going to be doing any more. So I think sometimes for the patient's sake you just have to walk in blind and, and, and take, you know, what they've been... ..hit with and, and, and, you know, empathise with them really.....and, and deal with it that way together. ADN1/P3/DNInt2

Whilst this can be seen as 'walking alongside' the patient on their journey, this approach clearly hampers a coordinated approach to care planning, and potentially leads to such plans being delayed or avoided.

These data draw from post-observation interviews with district nurses reflecting how they perceive their role, with a clear focus on the role of the relationship, the ongoing nature of care, and the role of both in facilitating excellent future care. These data from interviews with district nurses can be contrasted with data from interviews and observations which focus on the actual care observed.

CARE IN THE MOMENT

Immediate plans

When asked to reflect on their role or aims for the specific observed visit, district nurses usually conceptualise the visit in terms of immediate needs, often related to physical symptoms:

Well, mainly to make sure that the pain was still well controlled and that no other symptoms had developed. And obviously we talked about the lethargy one, and I kind of think he's perhaps doing a little bit more than, than he should really be doing.' ADN1/P1/DNint1

Symptom control, letting her know that the symptoms she's getting are quite normal, checking on the mental state and they're not getting, depressed through

the treatment and...getting appropriate action if...if that occurs.

ADN1SN1/P3/SN Int1

District nurses are aware that their immediate, as opposed to future, care aims are focused on ameliorating presenting problems.

Presenting problems:

The observed district nurse visits to patients were primarily monitoring visits – discussing issues and concerns rather than providing physical nursing care. Physical nursing care observed included taking blood pressures, blood samples, and inspecting skin. No provision of personal care such as meeting hygiene needs was observed, although district nurses report providing this to some patients outside the observed encounters. The care provided is demonstrated primarily in the spoken interactions between patients, carers and nurses. These focused on attending to issues presented during the interaction, often prompted by a general question:

ADN3: Any, any new sort of signs or symptoms?

P1: I get a lot of pain now.

ADN3: Yeah.

P1: Getting more pain.

ADN3: Did Doctor [GP's name] up the Oramorph [liquid morphine]?

P1: She left me one bottle and

ADN3: Right. But you know your tablets?

P1: Still I'm not 100 percent...

This interaction is typical in its focus on a physical symptom (pain) and discussion of a pharmacological response (analgesia). Nurses frequently initiated or expanded these discussions, enquiring above about a patient's symptoms, and here exploring the issues with a patient's legs:

P2: You know, he came and then Dr [GP name] rang and then [lymphoedema nurse name] I rang so... I'm having terrible trouble with my legs.

BDN1: Just explain, talk me through what the problems are with your legs, what your symptoms are.

P2: Well, it all started the day after I'd had my CT scan, they just started to swell.

BDN1: Yeah.

P2: And they just feel as though I'm breaking through my skin.

BDN1: I'm going to wash my hands in a minute and I'll have a good look at them again

Whilst the focus on symptoms in the district nurse consultations frequently stems from the nurses asking about an update on physical symptoms, they also respond to patients reports of new physical issues:

Patient and nurse are sitting at opposite ends of the sofa in the patient's living room, facing each other. The patient has started to discuss a recent outing:

P1: And I was driving the car on Friday, [sister's name] was with me and, err, just around [local town] and I went a little bit, I don't think it was dizzy, I just felt a bit far away, it was only for a few seconds.

CDN1 Right, right.

P1: You know, so I just pulled in. And, err, it went off. It just unnerved me a little bit.

CDN1 Yeah, yeah, it's frightening, isn't it?

P1: Yes, it is.

CDN1: As well, when you're driving and you...

P1 Yeah, I wondered if it was, sort of, blood pressure or...But, then, nobody ever does my blood pressure, doesn't...don't seem to, you know

CDN1: Do you want...do you want it doing?

P1: Well, I wondered if it might be...

CDN1: Mm, we'll have a look (nurse starts to reach into bag by her feet and get out her sphygmomanometer whilst they continue to talk)

P1: I mean, I don't, well, you know, I don't faint but...

CDN1: Yeah. Do you take any medication for your blood pressure?

P1: No.

CDN1: No. Okay, so it's never been a problem with you...

P1: No.

CDN1: Because you will have had it checked, I'm sure, when you go to see the GP, they nearly always check your blood pressure... or doesn't he?

P1: Well, I...I'm a bit, well, you see... And, so, I told Dr [GP name] and I said, do you think you should check it, and he says, oh you've enough worries without blood pressure, he said, and he didn't do it!

CDN1: Didn't he? Oh well. I'll do it... (pause whilst district nurse focuses on taking blood pressure and patient watches her) ... so there we go, one forty eight...

P1: Back up?

CDN1: It is, yeah, mm.

P1: Oh, very good. So it's...

CDN1: Tick that off your worry list!

District nurses were anxious to emphasise that they were performing a wider, more holistic assessment when performing physical tasks, which might not be immediately apparent:

'I'm looking around the home and thinking well everything is in place, so she's still functioning, but the issue is she's not functioning at that level, and it transpired that well I'm finding it difficult to shower now, so although I can walk around down here, and there's no evidence down here that I'm struggling, I'm actually finding it a bit more difficult with the stairs and the shower is now an issue, you know, so it's that listening to what she's saying, using your skills, your clinical skills, well, fitting within that social context.'

BDN2/P2/DNInt1

Short term planning

District nurses engage in short term planning with patients on a regular basis, and emphasise their coordination and liaison role:

I just see my role as trying to... being her advocate, trying to get things moving so if she has a problem, um, I... I see my role as dealing with it, um, especially, you know, connected with her health and with the rest of the family, if there's something she can't deal with then I will put her in touch with the right person. A DN3 P1

The way that district nurses respond to immediate needs with care coordination is exemplified by this extract, which reflects different parts of a visit which culminates in the district nurse arranging the admission of the patient:

ADN3: [discussing pain relief] I wonder if (GP) called clinic, about your...er, the pharmacy, you know, about that going up to 210. I'll, I'll give them a ring. I've got to go the clin...er, pharmacy so I'll mention it to them. And have you had your antibiotics?

P1: No, I'm just doing that now.

(later in visit)

ADN3: Do you want me to see if I can get you in [to the hospice]? 'Cos I think...you've been in anyway haven't you, ADN3P1?

P1: To the day centre.

ADN3: Yeah. No, but didn't you go in as a patient? No. No.

P1: And they do it better than (local hospital) don't they?

(later in visit)

ADN3: Oh yeah, yeah. Oh you're on...yeah, you're on domperidone, yeah. You're on quite a lot really but we don't seem to be getting you sorted do we? Well, what I'll do I'll phone the, the (name of GP surgery) and see...shall we see who's on GP wise? Have you had some of your coffee? [Pause DN gets her mobile phone out and starts to ring the surgery. There is a lot of silence whilst we're waiting for her to dial and hear what is being said]. I'm in a queue.

Such liaison and responding proactively to immediate physical needs was common place in observed visits, in contrast to the seeming avoidance of what would usually be termed 'advance care planning',

Advance Care Planning

Absent from most observed interactions was any form of advance care planning. Whilst district nurses clearly recognise its importance, this seems to be an aspect of care rarely

articulated during the observed visits. On occasions when future care is discussed, this tends to be in relation to physical symptom management, such as this discussion of hospice care:

Following discussion of patient accessing local hospice for day complementary therapies, and that had introduced her to the hospice.

DN1Sr2: It wouldn't be such a big wrench, I suppose, if you had to utilise them [the hospice] for something.

P4: Well, that's right.

DN1Sr2 Whether it be for therapies or for some...sometimes they go in there just to...if your symptoms became uncontrollable.

P4: That's right, yeah.

DN1Sr2: You know, you can go in for symptom management.

P4: Yeah, yeah. Or pain as well.

DN1Sr2: Yeah, pain, there's all kinds.

P4: Yeah, yeah.

DN1Sr2: It's not...I think people forget how, you know...

P4: Well, you just think you're going in to die, don't you, straight way.

N: I know, you do yeah, and you can't...

DN1Sr2: I mean, you can't get away from it, that's what you...it's your first thoughts.

There is shared acknowledgement that hospice can be negatively perceived, and an opening of a conversation that care may be available for specific symptom control requirements. Rather than being

nurse initiated, patients appear more likely to raise issues of prognosis and planning, usually to emphasise that they don't want to discuss it at the moment, a position rarely challenged by the nurses:

I haven't needed anybody at all, even...I think, I think I've only...twice it's all caved in on me where I've thought, you know, this is bad, this is major. But I climbed out of it thinking well, we...none of us know anything do we really. So just live today and see what tomorrow brings, and it's working. I want to get this chemo out of the way and book a holiday and go somewhere, do something. DN4P1

Views of patients and carers

Patients recognised and responded to their lived experience of district nurse care. They clearly articulated expectations when interviewed that relate to care updates and symptom related care:

That we see...like she said last time, I'll get in touch with you the week after you've seen (consultant). It's normally, erm, I think she wants to know what they've said, obviously, and then just keep a check that the symptoms are...I mean, because I had problems with my chest, we're a family like that, and she said, well, I think you need to see the doctor, so we did that and I got antibiotics, so I think it's just if anything comes up, erm, she can help me with it and she does, you know, so that's how we've arranged it and if I need her, I know where she is, so... BDN1 SR1 P4

Patients appreciated the care offered by district nurses, and noted that this made them feel supported appropriately:

But he always makes sure, he makes sure, you know, we've had a conversation...however short or long, doesn't matter, but he always asks how

I'm doing and how I'm feeling and yeah, it's, it's good, it's reassuring. It's just nice to know you've got somebody there that...I mean I did only [laughs] fall apart on him the one time, but the way he reacted was just, you know, what you would...what you need...at the time. ... CDN4 P1

Discussion

This study shows that whilst district nurses operationalise immediate aims of care, they appear to find it more challenging to help patients and their carers to effectively plan care further into the future. District nurses acknowledge that the aims of individual visits focus primarily on the assessment and management of physical problems, and this is reflected in observations of the care given. However, district nurses also articulate longer term aims related to building a relationship with patients and families to facilitate advance care planning and improve the quality of care at the end of life, but there is scant evidence of delivery of such advance care planning in the care observed. Patients appear to meld their expectations of care around that which is provided, and appreciate the symptom control and supportive monitoring role offered by district nurses.

District nurses appear able to facilitate relationship building, and communication with, people towards the end of their lives. Other studies support this, demonstrating that district nurses become 'trusted friends', responding to needs and desires, with this relationship underpinning care provision and profoundly influencing the nature of the psychological support given (Offen, 2015, Pusa et al., 2015). They recognise their challenging roles in breaking bad news about transitions to dying, but find timing such conversations difficult, and feel they have limited preparation for this aspect of their work (Griffiths et al., 2015). As reflected in the research reported here, they may also feel that they lack accurate information to conduct such conversations, or that others such as doctors should be responsible for prognostic and decision-making conversations (Anderson et al., 2019). These challenges may mean that district nurses struggle to enable conversations about particular topics.

Advance care planning is considered important to the delivery of high-quality end of life care. Whilst plans can be formalised as 'living wills' or advance directives, evidence is scant that such formal approaches facilitate communication, and many patients prefer that planning is a repeated process of discussion of prognosis, concerns and preferences (Lewis et al., 2016, MacPherson et al., 2013). This allows time for gradual adjustment, and the re-visiting of discussions to enable patients and families to take some control in the process of transition (Collins et al., 2018). This model appears to suit the visiting patterns of district nurses, and so it is disappointing that they appear not to be exploiting these opportunities. The few other observational studies of district nurses providing palliative care echo these findings, reporting a focus on physical symptom management and enabling talk about liaison, facilitation and referral rather than advance plans (Griffiths et al., 2013, McKenzie et al., 2007). It may be that they feel they do not have the time or skills to have such emotionally charged and subtle conversations, or that they do not have authority if information disclosure is required (Minto and Strickland, 2011).

There is evidence that with appropriate training and support that district nurses are able and willing to communicate differently with people towards the end of their life, facilitating advance care planning (Blackford and Street, 2012a, Blackford and Street, 2012b). Indeed, emerging evidence shows that changes in district nurses communication style can be marked and sustained with appropriate training and support (Griffiths et al., 2015). Given that district nurses perceive the importance of, and their involvement with, such communication and future care planning, it is likely that such skills-based investments, as recommended by district nursing bodies, may have profound impacts on care experiences of those towards the end of life (Queens Nursing Institute; Queens Nursing Institute Scotland, 2015). This may enable a greater match between what district nurses perceive as important, and what they were observed enacting in practice.

Strengths and limitations of the study

There are great strengths in the observational nature of this study, enabling understanding of what is done, rather than what is said. However, it may be that district nurses facilitated access to a particular type of patient, perhaps earlier in their disease trajectory, and with whom they had a strong relationship. All those identified as potential participants had a cancer diagnosis, despite district nurses providing palliative care to those with other diagnoses. It may be that district nurses felt more comfortable with patients with cancer diagnoses or received more such referrals. The findings of this study may not be as relevant to those with different diseases and different illness trajectories. Given, however, how ill and sick some participants were (many died before second or third interviews could be conducted, some were admitted to hospital etc.), this was certainly not the case for all those who participated. However, no patients receiving 'hands-on' care at the very end of life were observed.

Conclusions

District nurses are integral to provision of palliative care at home, and their care is valued. However, what they say they do is not necessarily borne out in practice, with a focus on physical symptom management evident from observation of visits. Further research should focus on tracking the effects of promising educational interventions that may facilitate a broader approach to care, but without taking additional, unavailable, time.

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