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Caring for people living with dementia in their own homes: a qualitative study exploring the role and experiences of registered nurses within a district nursing service in the UK

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Caring for people living with dementia in their own homes: A qualitative study exploring the role and experiences of registered nurses within a district nursing service in the UK

Abstract

Background: In the UK, district nursing services (DNS) deliver care to people in their own homes and have regular contact with people with dementia. Research conducted with nurses working in similar roles outside the UK suggests their contribution to high quality dementia care is limited by compassion fatigue, lack of dementia training and low levels of confidence. However, there is a paucity of research exploring the role and learning and support needs of nurses within DNS.

Methods: The study was informed by a descriptive phenomenological approach. The aim was to gain insight into the role and experiences of nurses caring for people living with dementia at home. Semi-structured interviews were conducted with a purposive sample of ten nurses working in DNS. Data were analysed thematically.

Results: Five main themes were identified: ‘Home as a care setting’ reflected how delivering home-based care shaped participants experiences of caring for people with dementia; 'Taking it in their stride' revealed how participants adapted and responded to the complexity of care needs for people with dementia; 'Complexity and unpredictability’ related to the unpredictable nature of people with dementia’s care needs and the impact this had on participants’ workloads; 'Expertise and support within the wider team’ detailed which networks nurses used for advice and support to manage the complex needs of people living with dementia at home; ‘Specialist support’ identified the need for structural changes and resources to enable the nurses to deliver the care needed.

Conclusions: This study enables better understanding of the role of DNS in supporting people with dementia to live at home. This is important for defining how dementia care can become effectively integrated into primary care. Recommendations include improved models of care, which factor in specialist nurses, additional time for home visits, and greater emphasis on education and training.

Keywords

- Primary Health Care
- Community Health Nursing
- Dementia
- Qualitative Research

Summary Statement of Implications for Practice

What does this research add to existing knowledge in gerontology?

- This is the first study to our knowledge to ask nurses working in DNS in the UK about their role and experiences of caring for people with dementia at home.

- This paper explores the scope and skill-set of generalist nurses caring for people with dementia at home in the UK and their ability to manage complex care situations.

- DNS are key to supporting global and national 'ageing in place' policies that advocate people with dementia live at home for as long as possible.

What are the implications of this new knowledge for nursing care with older people?

- The findings help distinguish the role of nurses in supporting older people to live at home and identifies the knowledge and resources needed to provide good quality dementia care.

- Developing dementia training programmes and best evidence clinical toolkits would equip nurses with the skills and education required to care effectively for people with dementia at home and their families.

How could the findings be used to influence policy or practice or research or education?

- Understanding the unique contribution of DNS is important for defining how dementia care can become effectively integrated into primary care.

- Improved models of working that factor in additional time and specialist nurses in dementia and palliative care are required to meet the needs of people with dementia living at home.

- Further research is needed to establish the evidence and embed the role of DNS in models of primary care provision for dementia.

Background

Globally, dementia prevalence is increasing as people live longer. In the UK, approximately 838,693 people live with dementia (Nichols et al., 2019). To secure the best outcomes for older people and reduce financial costs associated with old age, many countries pursue an 'ageing in place' agenda (WHO, 2015), where people live in their own homes and communities safely, independently and comfortably, regardless of age, income or disability (CDC, 2013). However, living at home with dementia can be difficult. Dementia is characterised by progressive cognitive and functional decline causing problems with performing activities of daily living and jeopardising independence. Furthermore, people with dementia often have multiple comorbid conditions, which are associated with reduced quality of life, caregiver burden, and greater healthcare use (Zhu et al., 2017). This context creates demand for high quality primary care for people with dementia and their families.

National UK policy advocates timely dementia diagnosis, access to high-quality health and social care after diagnosis, enabling people to live in their homes for longer, and supporting people to die with dignity in a place of their choosing (DH, 2012, DH 2009). Primary care is the cornerstone of the NHS and a key partner in delivering the government's dementia commitments across the illness trajectory. It offers universal and comprehensive health coverage and provides a holistic approach to care, diagnoses and manages disease, prevents illness, protects health and wellbeing, and supports people in the final years and days of life. It also helps patients and carers navigate across care providers and settings. The general practitioner (GP) is the first point of contact for someone showing signs of dementia. They undertake an initial assessment and make a referral to specialist dementia diagnostic services.

After diagnosis, a person with dementia and their family should have access to memory services or multidisciplinary dementia teams for treatment and support (NICE, 2018). However, whilst memory services are effective at improving recognition of dementia, people with dementia and their families experience gaps in service provision following diagnosis and crises may occur as a result (Martin et al., 2018).

Primary care practitioners play an important role filling the gaps following diagnosis. One such group of practitioners is Admiral Nurses. The Admiral Nurse role was designed by the charity Dementia UK. These nurses hold a mental health nursing qualification and give expert practical, clinical and emotional support to the family carers of people with dementia. There are currently around 270 Admiral Nurses in post in the UK (Lyons, 2020) and most are employed by local providers of care (Bunn et al, 2013).

The largest group of healthcare practitioners in primary care are nurses working in district nursing services (DNS). These services are commissioned to provide skilled nursing care to people living in their own homes within a specified geographical area/administrative district. Each service consists of a number of teams, each comprising a district nurse and a number of community nurses and healthcare support workers. Nurses working in these teams are generalist nurses, who have either an adult nursing qualification (known as community nurses) or an adult nursing qualification plus a specialist practitioner qualification in district nursing (known as district nurses). The latter hold responsibility for the patient caseload and the management of the team.

District nursing caseloads mostly comprise patients aged over 65 (Murphy & Smith, 2017). The prevalence of dementia, combined with the age profile of their caseloads, means that nurses working in DNS have regular contact with people with dementia. At their best, DNS deliver an ideal model of person-centred, preventive and coordinated care, which can reduce hospital admission and help people to stay at home (Kings Fund, 2016). However, while community nurses and district nurses are experts in managing long-term conditions, their pre-registration education is orientated to learning about physical rather than mental health conditions (RCPsych, 2016). Furthermore, despite the policy commitment to supporting people with dementia across the illness trajectory, and the ageing in place agenda, there is a paucity of research exploring the role of nurses working within DNS, or their learning and support needs in terms of caring and supporting people with dementia and their families in the UK. Nevertheless, research conducted outside the UK suggests their contribution is potentially limited by compassion fatigue, lack of dementia training, and low levels of confidence (De Witt & Ploeg, 2016; Huang et al., 2013).

Evidence is needed that explains the contribution of district nursing in dementia care. This could help identify ways to improve quality in DNS and increase access to sources of support for people with dementia and their families in community and primary care. To address this gap in the literature, the aim of this study was to gain an insight into the role and experiences of nurses within the DNS when caring for people living with dementia and their families in the UK.

Methodology

Design

The study was informed by a descriptive phenomenological approach (Giorgi, 2009). This approach is indicated when little is known about an issue and the aim of the study is to make

clear and understand the most essential meaning of the phenomenon of interest from the perspective of those directly involved. Our aim was to understand how nurses make sense of and interpret their experience of caring for people living with dementia. In the descriptive approach, the researcher makes no interpretations but instead analyses participant descriptions and organises them into meaning-laden statements, gathering those meanings that are essential to the construct of the phenomenon under investigation (Penner and McClement, 2008).

COREQ (COnsolidated criteria for REporting Qualitative research) guidelines were adhered to for reporting the study (Tong et al., 2007).

Setting

The study was conducted in an NHS Community Trust commissioned to provide DNS to a diverse population within an administrative district in London, UK. Dementia prevalence in residents aged over 65 was lower than national figures although the dementia diagnosis rate was above average. An unpublished caseload analysis from within the local DNS revealed that 32% of patients had dementia and a further 13% were likely to have dementia but had no formal diagnosis.

Sample

The DNS comprised three daytime teams and one overnight team. It was anticipated that all qualified nurses working within these teams would be able to provide in-depth and detailed information about the phenomenon under investigation. To that end, we purposefully sampled both district nurses and community nurses from the daytime and overnight teams.

Recruitment was undertaken by AT, a district nurse working in the organisation where the study took place. AT promoted the study at team meetings. During these meetings, AT declared her position, and set out the purpose and scope of the study, the types of questions which were likely to be asked, the use to which the results were to be put, and the method of anonymisation. She also explained that participation was strictly voluntary and that if participants consented to take part but later decided they wished to withdraw, they could expect any data collected about them to be withdrawn and not used in the analysis or any future publication. At the end of each meeting, AT distributed participant information sheets to anyone expressing an interest in taking part. To minimise risk of bias, anyone working in ATs' immediate team were excluded.

In phenomenological research, there are no formalised methods to identify sufficient sample size (Francis et al., 2010). In this study, the concept of data saturation played a part in determining sample size, as well as the scope of the research, the nature of the research question, and the amount of useful information gained from each participant (Guest et al., 2006). To that end, we anticipated recruiting between eight and ten participants. This was revisited throughout the study with reference to the richness of the data obtained (Lincoln & Guba, 1985).

Procedure

Data were collected by AT, who had completed qualitative research training. Interviews involved collecting demographic information about year of adult nursing programme graduation, time spent in their current post, and then conducting semi-structured interviews using a topic guide. The guide was piloted with two practitioners sharing similar characteristics as the intended sample. Pilot data were not included in the analysis. Interviews were conducted privately in participants' workplaces at a time convenient to them. Written informed consent was obtained and interviews were audio-recorded with participants' permission. Participants were offered a copy of the study report.

The interviews were stopped after data saturation was reached and the study was deemed replicable (Guest et al., 2006). After 8 interviews, the point of data saturation was defined as being when two further consecutive interviews had been conducted with no new ideas emerging (Lincoln & Guba, 1985). Interviews lasted approximately 30 minutes. Data were collected between October and December 2018.

Ethical and governance approvals were obtained from the *redacted for peer review* Research Ethics Committee at *redacted for peer review* and the Health Research Authority *redacted for peer review*

Analysis

Data were analysed using a thematic approach. This involved a six stage process: familiarisation with the data and identifying items of potential interest; generating initial codes; searching for themes; reviewing potential themes; defining and naming themes; and producing the report (Braun & Clarke, 2012).

The researchers' identity, values and beliefs cannot be entirely eliminated from the analysis of qualitative data. All the authors had experience of working with people living with

dementia: AT and CM as district nurses, and JH as an Admiral Nurse and health services researcher.

To promote objectivity, the analysis was conducted as follows: (1) AT transcribed and anonymised recorded interviews verbatim (2) Word documents were imported into NVivo 12 (3) JH read and re-read the transcripts to gain familiarity, highlighted sections of text and coded them under preliminary descriptive titles (4) JH formed initial themes using these codes and titles (5) AT and CM independently reviewed the initial construction of themes from coded extracts and agreed with the allocation of codes or offered alternative perspectives (6) An iterative process followed whereby JH recoded data based on feedback and further cross checking by AT and CM until consensus captured participant experiences (7) JH, AT and CM met to further refine the codes and themes, which involved the rewording of some theme descriptions and collapsing of others.

Results

Participants included seven community nurses (CN) and three district nurses (DN). Post-registration experience ranged from 7 months to 23 years, with most having worked in primary care settings between 2 to 4 years.

Everyone regularly visited people with dementia; however, none had received dementia-related training in their current role. While some attended training in previous roles (for example, while working in inpatient or care home settings, or during preregistration or specialist practitioner qualification training), most learnt about dementia by caring for people on their caseload. One participant had experience of caring for a family member with dementia and another learnt relevant skills while caring for people with delirium in intensive care.

Participants described providing care across all stages of the illness from early-onset dementia to end-of-life care. Some participants were instrumental in identifying early cognitive changes and initiating a diagnosis, while others supported people with moderate levels of dementia, many of whom lived alone, or people with advanced dementia who lived with relatives.

Their role in caring for people with dementia was predominantly seen as being to ‘administer medication’ or ‘provide wound care’. However, some described a more ‘holistic’ approach which included ‘setting up care plans’, ‘supporting families’, ‘being responsive to emerging needs’ and ‘advocating’ for the individual. The priority was always that the person with dementia was ‘safe in their own home’.

Five key themes were identified: Home as a care setting; Taking it in their stride; Complexity and unpredictability; Expertise and support within the wider team; and Specialist support. These themes and sub-themes, together with selected descriptor quotes are shown in Table 1.

Insert: Table 1: Emergent themes identified from the qualitative narratives

Home as a care setting

This theme reflects how the home-based care environment shaped participants' understanding of the needs of people with dementia and their families. They gained insights that may not be as evident in other healthcare settings. Participants discussed the importance of the home for maintaining the person with dementia's psychological wellbeing, but also noted concerns about vulnerability, risk, and social isolation for people living alone, and the impact of caring observed on families.

Providing care for people with dementia in their own homes

Working with people with dementia challenged some participants' preconceptions about whether the person should remain in their own home:

> *"Before I started…dementia was this big unknown scary thing and actually it's not, they are still people…putting them in care homes isn't going to make them better".* DN3

Participants recognised the stress and disruption that the person often experiences when admitted to hospital or on their return home. Nearly all participants highlighted the importance of the home in preserving autonomy, routine and in promoting psychological wellbeing.

Being alive to potential risks, neglect and abuse

Participants were conscious of 'safety issues' within the home and through experience intuitively knew when a person with dementia was at risk of harm. They frequently performed mental checklists to identify risks related to concordance with medication and care packages, nutritional status, personal hygiene, lucidity, and susceptibility to self-neglect and household accidents:

> *"You will look at all of the safety issues, …if the carers are there, the patient is losing weight…the patient is more confused…, you're looking at whether the patient is taking their medication, if they have bruises, injuries, if they are talking sense. …you basically are risk assessing every day and going through a checklist…but there is no formal checklist, so you run through your experience and then you cope".* CN5

Factors related to the home environment sometimes placed both the person with dementia and the nurse at risk:

> *"…some become hoarders and it's cluttered…making it quite dangerous for you going in and also a falls risk for them".* DN2

Participants also described finding people living in neglected states and contacting social services to arrange temporary placements so risk-reduction strategies could be put in place, or to review support plans, arrange emergency payments, and organise household repairs:

> *"We were going to someone with dementia that had no food in, that was diabetic, and they released funds for the carers to actually buy food…and things like for broken lights and boilers."* CN4

<u>Recognising and responding to loneliness</u>

Several participants acknowledged the detrimental impact social isolation had on people with dementia. These concerns conflicted with their primary responsibility of meeting the person's physical health needs:

> *"I sometimes struggle to just keep it to health because…social needs and…health needs are so intrinsically linked…if they're happy and less isolated they are more likely to be taking their medication, more likely to be drinking enough and looking after themselves".* DN3

Efforts to increase people's involvement in community activities included referrals to befriending schemes and day-care services.

<u>Recognising impact on families</u>

Participants recognised the challenges families faced coping with fatigue, difficult behaviours, limited finances, lack of available help and how feeling overburdened could lead to a breakdown in care:

> *"Managing it, it destroys the families… He used to go up there like five, six, seven times a day just to make sure she is alright. …he said to me 'I would never, ever, ever put my mum in a care home, but I have to because she's not safe at home and I haven't got enough time'".* CN7

Participants regarded working with families, providing information about respite or advice and education about caring for someone with dementia, as key parts of their role. Families were supported through transitional periods including care home placement and end-of-life care.

Taking it in their stride

This theme reflects how participants adapted and responded to the complexity of care needs for people living with dementia, despite little relevant training. Compassion and empathy were used to build relationships with patients and confidence developed over time and with experience. Although participants were confident delivering many aspects of care, they felt less confident discussing advance care planning (ACP).

<u>Being compassionate and empathetic</u>

Building trusting relationships with people with dementia was of paramount importance. Participants described how their person-centred approach was often key to establishing a rapport:

> *"You just find something, a common ground... Like one was an actor…bring him back to his theatre days and we will talk about his acting. We have had one before with a catheter change and we play classical music to him because it soothes him".* DN2

This approach was underpinned by high levels of compassion and empathy, which provided comfort and reassurance:

> *"you just need to be very gentle and calm with them…you have to have compassion."* CN1

Once trust was established, the person would often consent to receiving care from the DNS but not from other health or social care professionals, particularly paid carers. Participants attributed this to paid carers sometimes struggling to communicate effectively:

"People don't understand how to talk to people with dementia…being very task orientated and not really engaging the patient…I don't find that carers have the time or give the time to be really kind and gentle". CN6

Empathic approaches helped to accommodate the person's difficulties and allowed time for information to be processed.

Caring with confidence

In general, participants felt confident working with people with dementia. Confidence was especially high for assessing the person's needs, administering care, coping with difficult behaviours, and assessing safety and capacity to make decisions:

"…I would know what to do in terms of their safety, in terms of identifying whether their support mechanisms are working or not...yeah, I feel confident". CN5

However, some participants acknowledged the limitations of their generalist knowledge and skills and wanted to work more effectively with families:

"I think I could be better trained and better skilled…to really give the families some constructive and really effective nursing intervention..." CN6

Confidence with advance care planning

Participants had mixed responses to discussing ACP. Several did not feel confident or perceived ACP to be the responsibility of more senior or specialist nurses:

"More confident than I did before I did the [district nursing] course. I spent a bit of time with the palliative care team, but I still feel that it's not really [our] remit. We can broach the subject…and we can discuss elements of what ACP might mean". DN3

Some nurses had received training and felt confident but observed the need for sensitivity of timing when ACP could be discussed. ACP should take place when the person with dementia still has capacity to make decisions about their future. Some participants only felt confident discussing end-of-life care when the person had entered the dying phase of their illness:

"…about the point they get to the end-of-life stage…then you are kind of in a more comfortable position to discuss end-of-life because deterioration is happening on a day-to-day basis and everybody…can see that". CN4

Complexity and unpredictability

Participants described the complex and unpredictable nature of people with dementia's care needs and the impact this had on their workloads. Participants tried to respect the person's wishes and advocate for their care needs, whilst recounting dilemmas due to lack of time, difficulties in coordinating care, and conflicting views about mental capacity.

Dealing with unpredictability

Participants reported frequently coping with unpredictable behaviour, such as difficulty gaining access because the person had forgotten they were visiting. Equally, difficulties arose when the nurse had not previously met the person, or was inadequately prepared before visiting:

> *"I was too rushed...I didn't properly read his notes before I went...I put the key back in the key safe [outside the front door] before I went into the house and the door locked after me so there was no way to get out and then all the doors on the ground floor had the knobs taken off…and I was like 'oh god…'".* DN3

Sometimes the person was resistive to care or had misplaced their medication or wound care supplies. Some nurses were afraid to visit people known to be aggressive and found combative behaviour frightening, whereas others were more confident in managing agitation:

> *"Nurses were really scared to go in... when I got there, he's started shouting and I was firm with him and I just said …very calmly "I've just come to do my work as a nurse", "Yes I know you are a nurse," I said "Exactly so can we work together" …and then he was calm".* CN8

If necessary, nurses arranged for family members to be present or visited in pairs.

Time to provide the care needed

All participants reported having insufficient time to spend with people with dementia due to the extra time needed to offer reassurance and explanations, or to deal with unforeseen issues:

> *"With a patient with dementia unfortunately it tends to be very complex because they've lost their keys, they've lost their tablets, they don't know who you are; you*

have to do all the introductions and the reassurance again. …it's long visits, you need a lot of time and a lot of patience". CN7

One participant described taking an hour to persuade someone to allow her to administer an eye drop. Needing to spend additional time with the person also impacted on other patients:

"Even if you spend 15 minutes it's not enough because that fluctuates…it causes a problem because while you do that your next diabetic patient is still waiting for [their insulin] to be able to have supper". CN5

To avoid the impact of an extended visit on other patients, nurses would often return later to complete planned activities.

Continuity of care and carer

Alongside needing additional time, people with dementia and their families wanted the same nurses visiting. Several participants recognised the value of continuity, as the person was more likely to engage with their care:

"She tends to relate to people she knows…if you ring more than once then you will be standing outside because they know it's not their regular nurse...the patient will respond to…familiar faces". CN5

Whereas lack of continuity had the potential for failing to detect a deterioration in a person's health:

"Someone with a [urinary tract infection], if it's the first time I've seen them am I going to know that they are not normally like this? I could miss that until I've seen them again and they are a lot worse...". DN3

Despite the benefits and risks associated with continuity, participants explained how operational issues meant it was not always possible to send the same nurse.

Capacity, choice and decision-making

Several participants described difficulties relating to mental capacity and supporting personal choices regarding treatment and living arrangements. This was particularly relevant when someone was living in a neglected state and nurses did not think the person had full capacity:

"It's hard because you've got that fine line between having capacity and not having capacity. And you can quite clearly see somebody does not have capacity; however, they are deemed to have capacity, so they're allowed to continue in the environment they are in...that's the frustrating part for me". DN2

For others, the Mental Capacity Act (2005) has helped clarify issues:

"The Capacity Act...has actually helped and made things quite a bit clearer... We were already doing it; we were already making those judgements, but I think the Act actually helped clarify for people working with dementia". DN9

Advocating for people with dementia

Participants described their role in advocating for people with dementia and supporting personal choices to stay at home. They formulated intensive support packages, despite uncertainty about whether these would be funded:

"…from their previous wishes they want to stay home and…you can get a whole team involved for them to devise a daily plan; what to do in the morning, what to do in the afternoon, when they go out, what the carers will be doing. So that way you support someone at home. But equally it's an issue of funding whether [commissioners] would want to fund that sort of care package or…want the person to be in a specialist care home". CN5

Some nurses encountered lack of clarity about who had power of attorney and needed to act as advocate for the person with dementia:

"…relatives where you go in and there is a question over whether they actually have power of attorney or not…we have no way of checking at that point... In those situations, we are an advocate, we will only administer or do what we think is appropriate and what is actually prescribed". CN4

Also, when professional judgements differed participants had to challenge GP's and other professional's decisions to get the care needed.

Coordinating care and navigating care systems

Participants voiced concerns about the lack of post-diagnostic support from memory services:

> *"Memory services do a great job, but I think that the follow through care leaves a lot to be desired…once they are back into the community there is very little… maybe six monthly they will ring you, ring the family and just say 'oh how are things'…that's pretty much it."* CN6

They also described challenges arising from multiple providers being involved in the care of people with comorbidities and visits conflicting with other appointments. For social care, nurses recounted occasions when they supported paid carers by providing advice on nutrition and visit timings for specific patients. Others voiced concerns about the absence of a partnership approach and the reluctance amongst paid carers to escalate concerns:

> *"I've come across patients…sat in their faeces. I arrive maybe at midday and a carer [has] been early in the morning and…it will actually say in their notes...so and so declined personal care this morning…[But] they don't tend to liaise with us enough. Of course, there are problems…[people with dementia] are one of the most challenging groups. But talk to us, share that with us, we have suggestions."* CN6

Expertise and support within the wider team

This theme reflects the resources participants could access to help meet the complex needs of people living with dementia at home. Participants described utilising a range of individuals and agencies but predominantly sought advice from their colleagues and GPs.

<u>Sources of help</u>

Participants described having a broad network of support available, but usually sought support from their immediate team:

> *"We've always got a lot of support in this team, so if you don't know, you've got a whole team with more experience on the end of the phone".* CN7

Unusually, one team employed a dedicated mental health nurse to improve case management for people with physical and mental health problems and was a popular source of advice and support. Beyond their immediate team, the GP was instrumental in deciding which 'care pathway' to follow. Advice was also sought from palliative care teams for people receiving end-of-life care, community pharmacists, ambulance and NHS helplines, social services, memory services and charitable organisations such as the Alzheimer's Society. Families were also viewed as useful sources of support.

Specialist support

This theme reflects the specialist support participants indicated was required to improve care provision for people living with dementia. They sought structural changes and resources that would benefit people living with dementia and their families and were equitable to those received in other illnesses such as cancer.

Better services for people with dementia

Participants identified the need for further involvement from memory services pre- and post-diagnosis, more specialist care homes, additional information about services, communication toolkits, better access to telecare, and meaningful activities for housebound people. They wanted stronger nursing leadership and standardised dementia care plans to help improve care. Several repeated the need for increased time allocation and continuity of care:

> *"The amount of time you get to spend with that patient. …more consistency of care...it helps to have that established relationship and with the family as well, they like to see the same face".* DN3

Specialist dementia nurses or link nurses

Several participants identified needing practitioners with expertise in dementia such as Admiral Nurses, or link nurses to work alongside them and provide specialist advice:

> *"Having a dementia link nurse that gets the appropriate training and can then be there for the other staff... I mean we have link nurses for tissue viability, we have link nurses for palliative…but we don't have one for dementia".* DN2

Specialist training in dementia needed

Most participants wanted additional training to equip them with better knowledge and skills to pass onto families and paid carers and help improve care:

> *"…it would be good to have some dementia modules and…do practical role playing because…it's all very well saying this is what someone with dementia needs…it's never going to be one size fits all."* DN3

Discussion

Summary of findings

Our study asked participants working in DNS about their role and experiences of caring for people with dementia at home and these findings reveal the distinct contribution these nurses make. Participants described having considerable contact with people with dementia and managing increasingly complex situations despite relatively little training in this field. Key elements of the role involved ensuring consistency of care provision, providing carer education and support, navigating care systems and coordinating care packages. These accounts are important as dementia prevalence is increasing and the integration of dementia treatment and care into primary care is required to meet the long-term needs of people with dementia (WHO, 2017). Hallberg et al., (2013) mapped dementia care services across eight European countries and found care delivered at home included the most extensive range of activities, such as needs assessment, adaptation of the home, assistance with activities of daily living, nursing interventions, rehabilitation, and multidisciplinary team reviews. The shift in focus to care at home means it is important that people with dementia are cared for by a skilled and competent workforce (WHO, 2017). Better awareness of DNS ability to support people with dementia and comorbidity issues helps us to understand how people living with dementia can be supported to remain at home for as long as possible.

Dementia education in nursing curricula remains inadequate and lacks relevant practice-based experience (Alushi et al., 2015, Surr et al., 2017). Consequently, low competency amongst community nurses in detecting and caring for people with dementia is attributed to diagnostic overshadowing and lack of relevant skills training (Harrison-Dening, 2019; Thomas, 2010). Dementia is the most common mental disorder DNS encounter (Haddad et al., 2005) and many participants reported being able to distinguish difficulties due to cognitive impairment and identify possible dementia in people they visited. Similarly, Bryans et al., (2003) found DNs had high levels of knowledge and confidence in identifying dementia and managing co-existing mental health and behavioural difficulties.

Previous studies in the Netherlands found DNS involvement was a predictor for institutionalisation, which was associated with co-morbidity and complexity of care needs (Vernooij-Dassen et al., 1998, 2000). While people with dementia are vulnerable to risks associated with wandering, self-neglect and exploitation by others, overestimation of

potential harms may lead to risk-averse approaches to care such as unnecessary admission to care homes (Evans et al., 2017: Taylor et al., 2018). DNS care for people who are housebound, so do not regularly encounter other health professionals (Dixon & Thompson, 2018). The relationship with their patients is distinctive as care is provided in the home environment and this familiarity enables a unique therapeutic relationship to be established (Heaslip, 2013). This relationship allowed participants to provide care in quite exceptional circumstances at times, particularly when the person was living in neglectful states or highly agitated. In the absence of any standardised care plans for dementia, participants described carrying out daily mental and physical wellbeing checks to identify potential risk factors and did their best to overcome any challenges that arose. They could identify the psychological impact of having dementia, especially due to isolation and understimulation and observed when relatives were feeling burdened. Where necessary participants signposted the person or family carer to additional community support services or liaised with other agencies to arrange enhanced care packages. Overall, our participants described successfully providing continuity of care to people with dementia across the illness trajectory. This finding is significant, as it suggests an adaptability and responsiveness in DNS to meet the needs of people with dementia and care for them at home and this should be further evaluated.

Less confidence was evident regarding ACP, although participants were confident supporting people during end-of-life care. Reluctance to discuss ACP is not uncommon due to lack of clarity about which health professionals have responsibility for this, or assumptions that family carers know the person's wishes (Lamahewa et al., 2018). Hallberg et al's (2013) also found a lack of palliative care approaches and implementation of advance directives in dementia services across Europe. Services need to be proactive and responsive in providing appropriate and timely support for people with dementia (DH, 2009). Participants wanted additional time for visits, access to specialist training and the availability of specialist nurses to enable better service delivery to their patients with dementia.

Strengths and limitations

Limitations of the study were that participants were all based in the same NHS Trust. Dementia services are fragmented and there is variability in care delivery across Trusts (Frost et al., 2020), so obtaining perceptions from DNS in other organisations would have been of interest. Interviews were undertaken by a DN from the same Trust, which means there is a potential for participant response bias. Although the interviewer did not work directly with any of the participants it was possible that the nurses interviewed wanted their

experiences to be perceived as being positive. Nevertheless, participants provided candid accounts of their experiences, which included criticisms of the lack of training, leadership, and guidance on care planning for people with dementia.

Insert: Figure 1: The role of district nursing teams in supporting people living with dementia at home

Clinical and educational implications

Our findings suggest that DNS have a clear role in caring for people with dementia at home and Figure 1 outlines how the nurses interviewed provided this care. It was evident that participants were able to competently meet a diverse range of needs for people with dementia on their caseload. However, improved models of working that factor in additional time and staffing such as specialist nurses in dementia and palliative care would allow DNS to meet the needs of people with dementia more effectively.

Participants identified the need for more specialist training and greater emphasis is required on dementia training and education to improve the knowledge of community staff and guide practice (WHO, 2017). Standards already exist for dementia education (Waugh et al., 2013) and can be used to develop bespoke dementia training programmes alongside best evidence clinical toolkits that would equip DNS with the skills and education needed to care for people with dementia and their families.

Policy and environmental implications

Dementia poses global health and economic challenges that will result in increased demands for health and social care services (Department of Health & Social Care, 2014). People living with dementia need stable environments and rising life expectancy and increased dependency mean more sustainable models of care are required (Kingston et al., 2017). Currently there is a significant shortfall of care home places in the UK and personalised, community based, and preventative care models are therefore critical to ensuring people with dementia receive the care and support they need and can help minimise the impact on the environment (Alzheimer's Society, 2021; NHS 2020).

Implications for future research

Further evidence is needed to determine if the participants' experiences are consistent across DNS nationally. People with dementia's needs are complex and multifaceted and

additional research is required to assess how effectively DNS meet the needs of people with dementia and their families. This should include obtaining people with dementia and their family carers' perceptions about the care they receive.

Conclusion

Exploring the accounts of nurses has enabled a better understanding and appreciation of the DNS role in caring for people living with dementia in the community. Care was provided across the illness trajectory from detection and diagnosis of dementia through to end-of-life and the involvement of DNS was instrumental across all stages. Our findings help distinguish the role of DNS in supporting people with dementia to live at home, but further research is needed to embed this role in models of primary care provision.

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Appendix

Research Reporting Checklist: Consolidated criteria for reporting qualitative research (*COREQ*)

Table 1: Emergent themes identified from the qualitative narratives

Themes	Sub-themes	Descriptor quotes
Home as a care setting	● Providing care for people with dementia in their own homes	"How important it is to keep people at home"
	● Being alive to potential risks, neglect, and abuse	"Everything's a risk in dementia"
	● Recognising and responding to loneliness	"All they do is sit"
	● Recognising impact on families	"Families struggle to care"
Taking it in their stride	● Being compassionate and empathetic	"Be patient and take your time"
	● Caring with confidence	"We have a fair amount of experience now with dealing with people with dementia"
	● Confidence with advance care planning	"Are they where they want to be, are they safe there and what else could be put in place"
Complexity and unpredictability	● Dealing with unpredictability	"Everybody is so different with dementia"
	● Time to provide care needed	"Ten minutes is not enough"
	● Continuity of care and carer	"They want to see the same faces"
	● Capacity, choice and decision-making	"You balance the need with the wishes of the patient"
	● Advocating for people with dementia	"We go in and you advocate for them"
	● Coordinating care and navigating care systems	"You do initiate those things; you do take the lead and start doing things"
Expertise and support within the wider team	● Sources of help	"Our nurses have got more experience; they have been in the community for longer"
Specialist support	● Better services for people with dementia	"Don't think they are getting enough support and information"
	● Specialist dementia nurses or link nurses	"We need a point of contact. Somebody to take charge of this"
	● Specialist training in dementia needed	"The more awareness and knowledge you have you can manage it better"