Title: 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

Running title: The role of district nursing and dementia care

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Abstract

Integration of dementia treatment and care into primary care is recommended to meet the long-term needs of people with dementia. A pragmatic qualitative study using an interpretivist approach was undertaken to gain insight into the role and experiences of nurses caring for people living with dementia at home. We conducted semi-structured interviews with ten nurses working within the district nursing service (DNS). Participants described having considerable contact with people with dementia and managing increasingly complex situations despite little training in this field. Five main themes were identified: Care takes place within the home; Taking it in their stride; Coping with challenges; Support networks; and What would help. The study enables a better understanding and appreciation of the role of DNS in supporting people with dementia to live at home. Understanding the contribution of DNS is important for defining how dementia care can become effectively integrated into primary care.

Keywords

Background

Globally, the prevalence of dementia is increasing as people live longer. Approximately 838,693 people in the UK live with dementia and most are aged over 65 (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 daily functioning and self-reliance. Furthermore, people with dementia often have multiple comorbid conditions such as diabetes, 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). Primary care is the cornerstone of the NHS and a key partner in delivering the government's dementia commitments. It offers universal and comprehensive health coverage and provides a holistic approach to care, diagnoses and manages disease, prevents illness, and protects health and wellbeing. 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 a specialist dementia diagnostic service. After diagnosis, a person with dementia and their family carers 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 (Wolfs et al., 2008), people with dementia and their families experience gaps in service provision following diagnosis and crises may occur as a result (Martin et al., 2018).

Community nurses play an important role filling the gaps in service provision following diagnosis. Community nursing encompasses a diverse range of nurses and those working in district nursing services (DNS) 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). They provide nursing care to people in their own homes and play a key role in avoiding hospital admissions and facilitating early discharge. They work in teams and their caseloads mostly comprise patients

aged over 65 (Murphy & Smith, 2017). The prevalence of dementia, combined with the age profile of their caseloads, means that DNS have regular contact with people with dementia. However, whilst these nurses are experts in managing long-term conditions, their preregistration education is orientated to learning about physical rather than mental health conditions (RCPsych, 2016). There is a paucity of research exploring the role of district nurses, or their learning and support needs in terms of caring and supporting people with dementia and their family members in the UK. 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). 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

We adopted an interpretivist approach and pragmatic qualitative design using thematic analysis. 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 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 one local DNS revealed that 32% of patients had dementia and a further 13% were likely to have dementia but no formal diagnosis.

Sample

Purposive sampling was used to select nurses working within the DNS with experience caring for people with dementia. In determining sample size, the guiding principle was data saturation. Given the homogeneity of the proposed sample, an *a priori* sample size for the first round of analysis was set at eight. After eight interviews, the point of data saturation was defined as being when two further consecutive interviews had been conducted with no new ideas emerging.

Recruitment was undertaken by AT, a district nurse working in the organisation where the study took place. AT promoted the study at team meetings, then emailed a participant information sheet to anyone expressing an interest in taking part. Inclusion was voluntary, and participants were offered a copy of the study report. To minimise risk of bias, anyone working in ATs immediate team was excluded from participating.

Procedure

Data were collected by AT, who had completed qualitative research training. Interviews comprised collecting demographic information about year of graduation and time in current post, 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. Data were collected between October and December 2018. Interviews lasted approximately 30 minutes. Data saturation was deemed to have occurred after ten interviews.

Ethical and governance approvals were obtained from the School of Health Sciences Research Ethics Committee at City, University of London (Ref: MSc/18-19/08) and the Health Research Authority (Ref: 250360).

Analysis

Audio-recordings were transcribed verbatim, anonymised and imported into NVivo 12. Data were analysed using a thematic approach. This involved a recursive six stage process: familiarising yourself 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). All authors contributed to coding the data. Preliminary analysis was undertaken by JH and findings were cross-checked and discussed with team members at each stage of the data analysis process. Coded data were organised into identified sub-themes from which emergent themes were ultimately derived.

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 community settings for 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 the DNS caseload. One participant had experience of caring for a family member with dementia and another learnt relevant skills whilst 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, whilst others supported people with moderate levels of dementia, many of whom lived alone, or people with advanced dementia who were living with relatives.

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

Five key themes were identified: Care takes place within the home; Taking it in their stride; Coping with challenges; Support networks; and What would help. 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

Care takes place within the home

Participants were asked about any concerns they had providing care to people living with dementia in their own homes. This theme reflects how the home as a care setting shaped participants experiences of caring for people with dementia. They described the importance of the home for psychological wellbeing, but also concerns about vulnerability and risk, social isolation for people living alone, and the impact of caring 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 nursing…I felt dementia was this big unknown scary thing and actually it's not, they are still people…and putting them in care homes isn't what's 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' 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, you would look if the carers are there, the patient is losing weight…the patient is more confused from day one to day two, 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 of them become hoarders and it's cluttered and 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 review support plans, arrange emergency payments, and organise household repairs, or to arrange temporary placements so risk-reduction strategies could be put in place:

"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

Recognising and responding to loneliness

Several participants acknowledged the detrimental impact socially 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 that 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 peoples' involvement in community activities included referrals to befriending schemes and day-care services.

Recognising impact on families

Participants recognised the challenges families faced coping with difficult behaviours, fatigue, limited finances, lack of available help and how feeling overburdened led to 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.

Taking it in their stride

Participants were asked how confident they were in providing care to people with dementia in their own homes and in discussing their preferences and choices for future or end-of-life care. This theme reflects how compassion and empathy were used to build relationships with patients and how 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 patient-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 him and 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 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.

<u>Caring with confidence</u>

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

"…confident enough that 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:

"On the level of providing emotional support, some practical kind of help or advice…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 a more senior or specialist nurse:

"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 the DNs' remit. We can broach the subject with the patient and with their family 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

Coping with challenges

Participants were asked about their experiences of caring for people with dementia and any specific difficulties encountered. They described the unpredictability of people with dementia's behaviour 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.

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<u>Dealing with unpredictability</u>

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 had the knobs taken off…and I was like 'oh god…'".* DN3

Sometimes the person was resistive to care or had misplaced their medication and woundcare 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 listen…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.

<u>Time to provide the care needed</u>

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 could impact on other patients:

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"Even if you spend fifteen 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 you 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 UTI [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 who does not have the capacity; however, they are deemed to have the 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 (MCA, 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 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 people with comorbidities care and visits conflicting with other appointments. For social care, nurses

recounted occasions when they had supported paid carers by providing advice on nutrition and timings for their visits to specific patients. But some 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

Support networks

We explored what networks and resources nurses used when they needed advice and support to manage 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.

Sources of help

Participants described having a broad network of support, 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.

What would help

Participants were asked whether any aspects of dementia care could be improved and what additional resources would help. They identified the need for structural changes and

resources that would benefit people living with dementia and their families and thought that these should be equitable to those received in other illnesses such as cancer.

Better services for people with dementia

Participants identified the need for more frequent involvement from memory services pre- and post-diagnosis, more specialist care homes, more available information and signposting to services, communication toolkits, better access to telecare, and the provision of meaningful activities for housebound people. The overwhelming need was for increased time allocation and continuity of care:

> *"The amount of time you get to spend with that patient. …also, a bit 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

Participants wanted stronger nursing leadership and thought better organised care, including the provision of standardised dementia care plans would help improve their care.

Specialist dementia nurses or link nurses

Several participants identified the need for 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

Training in dementia needed

Most participants identified the need for additional training as this would benefit more junior colleagues and would equip them with better knowledge and skills to pass onto families and paid carers to help improve care:

> *"…it would be good to have some dementia modules and not just online that you can actually go and attend 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

<u>Summary of findings</u>

This is the first study to our knowledge to ask nurses working in DNS about their role and experiences of caring for people with dementia at home and these findings reveal the distinct contribution that DNS make. Participants described having considerable contact with people with dementia and managing increasingly complex situations despite relatively little training in this field. Most importantly they described successfully providing continuity of care to people with dementia and did so with much skill and compassion. Their accounts are significant as integration of dementia treatment and care into primary care is recommended to meet the long-term needs of people with dementia (WHO, 2017).

Dementia is the most common mental disorder DNS encounter (Haddad et al., 2005) and many of the 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 higher levels of knowledge and confidence in identifying dementia and managing co-existing mental health and behavioural difficulties than practice nurses. 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). Our participants described providing care in quite exceptional circumstances at times, particularly when the person was living in neglectful states or highly agitated; they could identify the psychological impact of dementia on the person, particularly in relation to isolation and understimulation; and were observant of changing dynamics within family relationships that enabled them to recognise and respond to the needs of family carers. Where necessary they signposted the person or family carer to additional community support services or liaised with other agencies to ensure delivery of enhanced care packages. Less confidence was evident regarding ACP, although participants described being confident to support 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). Advocating for people with dementia to remain at home and maintaining their autonomy with decision-making was also evident. Ethical dilemmas can often exist, as competence to make decisions is not necessarily linked to the ability to live independently, so the person becomes dependent on family members and DNs to uphold their autonomy (Smeybe et al., 2012; Smeybe et al., 2015). When it became

apparent the person's needs would be better met in residential care settings, participants supported patients and families to make this transition.

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 and professional. Nevertheless, participants provided candid accounts of their experiences, which included criticisms of the lack of training, leadership and guidance in caring for people with dementia.

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

Clinical implications

The ability of participants to meet a diverse range of care needs for people with dementia was evident and Figure 1 outlines the role of DNS in providing care for people with dementia. Our findings suggest that new models of working are needed, that can factor in additional time and staffing such as specialist nurses in dementia and palliative care, to ensure DNS have the necessary resources to effectively meet the needs of people with dementia on their caseload. The need for dementia-specific resources to guide practice and training, including more advanced nursing skills were identified. This supports the recommendation that effectively integrating people with dementia's care into primary care requires greater emphasis on dementia training and education to improve the knowledge and practices of staff (WHO, 2017). Developing dementia training programmes and best evidence clinical toolkits would equip DNS with the skills and education they require to care for people with dementia and their families.

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.

<u>Conclusion</u>

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
Care takes place within the home	• 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"
Coping with challenges	• 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"
Support networks	• Sources of help	"Our nurses have got more experience; they have been in the community for longer"
What would help	• 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"
	• Training in dementia needed	"The more awareness and knowledge you have you can manage it better"

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

- Managing complex care needs
- Promoting autonomy & independence
- Risk assessment
- Wellbeing checks

Providing continuity of care

- Care coordination
- Referral to specialist services
- Educating & supporting homecarers

Liaison with other agencies

Supporting family carers

Signposting to community services

- Partnership working
- Information, education & advice
- Transitional support - hospital discharge, care home placement & end of life care

- Specialist information & support
- Promoting social inclusion