Trainee district nurses' understanding and perceptions of the palliative care key worker role: a qualitative study

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In the UK, the Specialist Practice Qualification (SPQ) was introduced in the 1990s, representing a professional practice programme for registered adult nurses working in the community or who aspire to be a district nurse (Nursing and Midwifery Council (NMC), 2022). District nurses who have undertaken the qualification are identified as palliative care key workers (Queen Nursing Institute (QNI), 2015; Department of Health, 2018).

The palliative care key worker acts as a single point of contact for patients with palliative and end of life care needs and their families to augment effective communication, interdisciplinary collaboration and person-centred care (Gold Standards Framework (GSF), 2009; Palliative Care in Partnership strategy (PCIP), 2017; National Institute for Health and Care Excellence (NICE), 2019; Marie Curie, 2021). The benefits of co-ordinating care as part of a palliative care help in avoiding poor symptom control and unplanned hospitalisations (Renehan et al, 2017; Martins et al, 2022). While support for the role exists among family caregivers (Betts, 2024), there is a lack of consensus about who should shoulder this role, its title, level of preparation and implementation in practice (Bone et al, 2016; Ling et al, 2017; Reeves et al, 2020; de Nooijer et al, 2021).

Evidence indicates the palliative care key worker may face an array of professional, clinical, cultural and organisational barriers that impede the effective co-ordination of care (Hasson et al, 2022; Vočanec et al, 2023). Knowledge pertaining to the preparation of the role is limited, but research suggests the role requires extensive knowledge of the patient's conditions (Törnquist et al, 2013), advanced communication skills and the ability to plan and collaborate care with members of the multidisciplinary team (Midlov and Lindberg, 2020; Walshe, 2020). While research has focused on trainees' views of the district nurse role (Young and Reid, 2021; Marshall and Sprung, 2023), no specific research on their views and understanding of adopting the palliative care key worker role upon qualification has been undertaken. This study explore the views and understanding of district nurse trainees on the role of a palliative care key worker within community based palliative care.

Methods

There is a gap in the evidence base, which explores trainee district nurses' views of the palliative care key worker role they adopt upon qualification. An exploratory descriptive qualitative design was adopted. Exploratory methodology was used to allow subjective verbal accounts to be obtained while describing variations (Polit and Beck, 2021). A descriptive design aims to collect examples told through the experiences of participants (Sandelowski, 2010). Combining both approaches enabled a more nuanced exploration to be achieved (Hunter et al, 2019). The research has the following objectives:

Abstract

Background: The district nurse is identified as a keyworker in community based palliative care. However, a dearth of research exists on trainees' views and understanding of adopting the role upon qualification.

Aims: The aim of this study was to explore the understanding and perceptions of district nurse trainees in relation to the palliative care key worker role.

Methods: Data was gathered via online semi-structured interviews (*n*=10) and the results were analysed using a thematic model.

Findings: The four evolving themes included: understanding of the palliative care key worker role scope and function; the level of preparation for the role; a juggling act and embedding the role in practice.

Conclusion: The themes highlighted various drivers and barriers that reflect a degree of incongruence with policy and practice. Recommendations to standardise the palliative care key worker role, underpinned by formal preparation and clearly defined responsibilities may enhance future development and implementation of the role.

Keywords: community • district nursing • key worker • qualitative research

Table 1. Interview questions					
Que	Questions: probes to be used throughout				
1.	Tell me the reasons that led you to want to become a district nurse? (Probe: Professionally, personally, financially)				
2.	How would you define a palliative care key worker role? (Probe: Do you agree this is the role of the district nurse, if not then who, if yes why? Who in your opinion has a key role in your team when it comes to coordinating tasks?")				
3.	What would you envisage the process of care to be with the palliative care key worker included? (Probe: Do you know how tasks and responsibilities are shared in the team?")				
4.	What do you see as the key competencies of the palliative care key worker role? (Probe: What are the key responsibilities of this role, who do/should they report to?)				
5.	What training are you aware is given to the palliative care key worker, do you think this is enough? (Probe: Is there anything you would include, change?)				
6.	What do you think are the key value of this role? (Probe: To the patient, family, healthcare team, health service)				
7.	What do you think are the key challenges (if any) of this role within the multidisciplinary team and across services? (Probe: What are the top 5 challenges?)				
8.	What do you think are the factors influencing the implementation and development of this role in practice?				
9.	Do you have any other comments that you would like to make?				

Table 2. Participant demographics					
Category	Response (<i>n</i> =)	Category	Response (<i>n</i> =)		
Gender		Age			
Female	10	21–26 27–34 35–44 45–54 55–56	2 3 2 3 0		
Length of time RN		Length of time in DN			
1–10 years 10–20 years 20 plus years	4 3 3	1–10 years 10–20 years ≥20 years	9 1 0		
Other qualification	s	Any previous positions in PC			
Yes No	3 7	Yes No	3 7		

- Explore trainee district views and understanding of the palliative care key worker role
- Explore the level of preparation they have received to equip them for the role
- Explore trainee district nurses' perceptions of the barriers towards the implementation of the role in practice.

Ethics

Ethical approval was obtained from the Ethics Review Committee of the affiliated university (REF 2019-12-3.9). All standard ethical principles including distress, disclosure, informed consent and data storage were followed. Participants received oral and written information about the study, and informed that their participation was voluntary and they could withdraw at any stage without detriment. A number code was allocated to each participant to guarantee confidentiality.

Participants and recruitment

Purposive sampling was used to recruit district nurses undertaking the specialist practice qualification at a higher education institution in one region of the UK. A gatekeeper, independent of the study, screened and emailed an information pack containing an invitation, a consent form and a participant information sheet to potential participants.

If interested, participants were asked to return their consent form with contact details to the researcher (LMcD). The researcher would then contact them to answer any outstanding questions and if verbal consent was obtained, proceed to set up an interview time and date.

A total number of 10 participants out of 38 district nursing specialist practice qualification students were successfully recruited to the study.

Data collection

Online, digitally recorded semi-structured interviews were undertaken between October and November 2022, lasting between 20–40 minutes. An interview guide underpinned by previous research in the area and the aims of the study (Hasson et al, 2022; Martins et al, 2022) was developed (*Table 1*). The interview guide was refined by palliative care academics and palliative care key workers.

To describe participants' demographics, a questionnaire was administered prior to the interviews taking place (*Table 2*).

Data analysis

Data analysis commenced with the MS Teams transcriptions being checked by the researcher, which helped to support familiarisation and identification of common themes between participants. All transcripts were anonymised by removing any identifiable information with pseudonyms. Transcripts were subject to the six phases of thematic analysis as outlined by Braun and Clarke (2013). To enhance rigour, two members of the tram (LMcD and FH) independently reviewed all the transcripts and agreed on three themes to present the best description and interpretation of the data.

Findings

Overall, three major themes emerged from the data analysis: understanding of the palliative care key worker role scope and function, preparation for the key worker role and implementation challenges.

Theme 1: understanding of the palliative care key worker role scope and function

All participants understood that responsibility for this role rested with the district nurse, as they had the most contact with palliative patients compared with other healthcare professionals such as the GP or hospice nurse. However, regardless of length of time working in the clinical setting, none of the nurses believed that the sole onus of responsibility should always rest on them, rather they felt it was a responsibility of each healthcare professional regardless of title.

'We are that main director, just to make sure everything comes together and to follow everything through with regard to the patient and family, we are that go to person, we will make regular contact depending on patient requirements that can vary over the period of time of care, this can be followed up by the nurses that we're working alongside, patients maybe click better with other people and that's the best person, not necessarily the district nurse because of their title.' (P3)

Participants understood that as a palliative care link worker, they would have responsibility to care for patients with varying progressive debilitating diseases, experiencing malignant conditions and other comorbidities that come under palliative care. Their responsibility was interpreted as being centred on the co-ordination and delivery of person-centred care to facilitate living well at the end of life.

'....Involved with planning and co-ordinating care, so it's about being there for the patient for the whole process and their end-of-life care because you're looking after them as a whole, making sure all those areas of holistic care are managed, you're in the centre of the whole patient-centred care.' (P1)

Although participants recognised the value of the palliative care key worker role, many highlighted that there is lack of clarification about their role accountability and responsibility. Nurses were worried that the role would be given less priority in practice and not promoted as a valuable aspect of the duties as a district nurse. As a result, the majority of participants indicated the need for more succinct protocols and training programmes specific to the palliative care key worker role for better awareness of the scope and function of the role within teams and across services.

'I suppose there is lack of understanding of the key worker role, and I would say I worked in the district for four and a half years and had no idea the district nurse was the key worker, so I suppose many other people are the same as social workers, the whole multidisciplinary team, do they realise that the district nurse is the key worker for palliative patients?' (P7) 'Palliative care isn't only cancer, it's COPD (chronic obstructive pulmonary disease), its dementia, we have heart failure, there's more palliative patients than before therefore the palliative care keyworker is something that needs to be developed, it is huge in our future and is just about giving us the right information so we can bring it to the right people'. (P3)

The scope of practice was perceived to be complex, especially for less clinically experienced participants, as it not only required the management of symptom relief but also the multi-professional collaboration, communication and support to ensure the physical, mental, social, spiritual and existential needs of the patient and family caregiver were recognised and responded to.

'You need to be competent in the management of or aware of what symptoms can develop and where are the most appropriate places to get help, if the patient has complex pain, I would contact the GP or hospice nurse, or if mobility had decreased I would make a referral to the occupational therapist or social worker to make sure that the correct equipment and services are in place.' (P6)

All participants recommended the implementation of the palliative care key worker role required time and support to ensure it was embedded into and across practice. They considered building collaborative relationships with other healthcare professionals, negotiating the role and gaining support from organisational culture and technological systems to be vital. To facilitate this, several participants called for investment in communication pathways, especially the sharing of patient referral and discharge processes to facilitate more streamlined ways of working.

'There is lack of communication, you're getting a referral for palliative patients just to do a palliative assessment, no information and when you phone afterwards for a handover the nurse is on break, and it's not just a case that they can be let go as there is a lot of support and services that need put in place, and I think that falls on them not understanding the role of the district nurse and what exactly we do in community' (P10)

Theme 2: Preparation for the key worker role

Findings indicate that preparation for the keyworker role was variable, limited and not bespoke to the role. From the 10 interviews, eight reported that they had no previous formal training specific to be a key worker. No participants were aware of any bespoke formal training, instead opportunities were ad-hoc and accessed via charitable hospice providers or specialist palliative teams over a day period.

'I had one day, it was a whole day supplied by Marie Curie, it was actually really good as sort of identified what the palliative care key worker role was because I'd never really heard of it before, and I know that sounds ignorant, but I had never really heard of it before I had taken the band 6' (P6)

'...a whole day [of training] was supplied by Marie Curie, and it was actually really good to sort of identified what the palliative care key worker role was because I'd never really even heard of it before. And I know that sounds ignorant, but I had never heard or understood it before'. (P2)

'I know in our team it was our manager who arranged for a talk by one of the Macmillan nurses about symptom management and as far as I am aware that's not something that's done on a regular basis but that was something we found beneficial. '(P6)

Mandatory training the participants accessed was task based such as syringe driver and medicines management, but they did not believe this reflected the nature of the key worker function. Instead, to prepare for the role, it was recommended that training be focused on symptom management, advanced care planning and advanced communication skills to facilitate managing the patient's physical, psychological and spiritual wellbeing and have difficult conversations around sensitive issues that are inherent to palliative care.

'Apart from advanced care planning I'm not aware of anything else, but advanced communication should be mandatory for the likes of palliative care especially when you're dealing with such sensitive information and is such a sensitive subject.' (P7)

Two less clinically experienced participants highlighted that they would like more grounding on what the expectations of the key worker role were, including clearly defined roles and responsibilities.

'Maybe more training sessions and joint with the Cancer Centre or the wards and with the district nurses and what our expectations are' (P4)

'...and starting my specialist practice qualification course, I didn't know enough about what the palliative care key worker role is. But maybe some sort of training on it would be good just to know exactly what it entails the job' (P5)

Although the specialist practice qualification may offer some degree of insight into the key worker role, suggestions of more extensive information and training to enable nurses to fully support the patient were suggested to be of paramount importance.

'There needs to be some sort of transition programme where you take part in a palliative session and where you're made aware of who the palliative links are with the Hospice and Marie Curie and just what the expectations

are of the district nurse as a key worker.' (P10)

Theme 3: implementation challenges

A key issue voiced by all participants was related to managing the increasing scale of the district nurse's practice. It was recognised that district nurses were already working to capacity, combining both clinical and managerial responsibilities. High workloads were perceived to be exacerbated by staff shortages and increasing referrals which they believed limited the time they had to spend with patients and families. Given this workload, all participants questioned how effective the district nurse would be in balancing the competing demands.

'We never close our caseload, we never have waiting lists like every other healthcare discipline, we don't have that luxury and you've constantly got staff turnover, and they leave because there is not enough staff or they don't like it so then you're constantly juggling with the managerial thing and the key worker role, and if you have all new staff they often don't have the experience to pick up on things like the key worker would.' (P5)

As a key worker, nurses felt that having adequate time and spending quality periods to develop trusting relationships with patients and families was necessary. However, all participants perceived that this would be compromised by high staff turnover and increasing number of complex patients spread over wide geographical areas.

'Time management is difficult as patients like to give you their whole story and symptoms and there are so many of them it's hard to manage the complexity of patients within your day-to-day role, and there are challenges with bigger areas to cover and trying to be there for the patient at all times.' (P1)

Participants felt that the pressures of meeting service demands could be detrimental to physical and emotional wellbeing of the district nursing staff. Many experienced nurses echoed this sentiment. However, addressing such issues is more difficult as they are more systemic rather than individual in nature.

'Often we are managing such big caseloads in large geographical areas it becomes difficult to divide yourself into 100 parts with being overworked and overstressed.' (P3)

Discussion

The findings demonstrate that the palliative care key worker role is perceived to be important to the remit of the district nursing teams (Department of Health, 2018; Midlov and Linberg, 2020; Walshe, 2020) as they spend considerable periods of time with patients and their families, providing support and enabling care to be delivered in the home environment in accordance with patients' wishes (Coldrick and Crimmons, 2019; Ward et al, 2021). Given

the multitude of malignant and non-malignant conditions that come under palliative care, it was suggested that numerous sources of professional input would be required at varying times, to support patients and families and ensure that complex needs are met. This indicated that the onus of the palliative care key worker role may not always be ideally placed on the district nurse, but rather should rest with each professional involved. Such findings reflect previous national and international research that suggest the palliative care key worker role to be context specific rather than role focused, and should be the responsibility of the professional who is most involved (Bone et al, 2016; Reeves et al, 2020). However, Mason et al (2016) and Reeves et al (2020) warned that if no one takes the lead in the coordination of care, it may have the potential to fragment identification of roles and responsibilities across palliative care services, which Betts (2024) reported to be detrimental to coordinated and continuous quality care.

Whilst the palliative care key worker role is advocated within national policies and strategies (GSF, 2009; NICE, 2021), they have been criticised as failing to recognise the complexity of practice and not including an implementation approach (Hackett et al, 2018). In this study, the lack of an implementation strategy underpinned many participants' concerns, which may attribute to variability of such roles in practice, perceived by trainee district nurse participants. Consequently, dissonance with policy and practice has potential to impact on the service provided to the patient and family caregiver. This disparity has been recognised by others, most recently Hasson et al (2022), who emphasised the lack of clarity of how the palliative care key worker role is implemented regionally and nationally and suggested an incongruence with policy and practice.

The findings of this study question the readiness of district nurse trainees to embrace the palliative care key worker role in practice. Many signified that vital elements of the role would require formal advanced communication and advanced care planning training, as well as enhancing knowledge and competence with symptom management. Such findings are not new and reflect previous suggestions (Törnquist et al, 2013; Midlov and Lindberg, 2020; Walshe, 2020).

Across the interviews, several perceived barriers to the implementation were reported. A key issue was the complexity of caseloads, unrelenting pressures in terms of unlimited referrals and reduced capacity within teams, which may in turn be detrimental to the effective palliative care key worker function. Such concerns are reflected in a review of work standards undertaken by the QNI (2022), which reported that district nurse workloads were far exceeding capacity, as caseloads are not capped. Resource issues, especially workforce shortages were commonly reported in this study, as a key challenge and warned that ongoing staffing issues ultimately impact on the capacity and capability of teams to perform their role as a district nurse, but also as a palliative care key worker. A qualitative study by Drennan (2019) further emphasised the evolving paradox with district nursing teams trying to

engage in increased anticipatory care for patients with long term conditions to reduce hospitalisation. However, most teams are often task focused because of demands of busy caseloads, leading to an emotional dissonance with the role which was evident in the findings of this study.

This study identified several factors required to ensure effective implementation of the palliative care key worker role. For example, efficient communication pathways were deemed by the participants to be crucial to ensure the key worker is given timely and accurate information from the point of referral and throughout the trajectory of the provision of the role. The results of this study reflect shortcomings in communication across primary and secondary care interfaces, which have the potential to inhibit the district nurse key worker, particularly the need to provide tailored communication to enhance care. Such findings are not new and have been reported elsewhere. Young and Reid (2021) highlighted the barriers of task orientated referrals lacking essential information, which contradict the nature of district nursing services. This is further recognised in research by Midlov and Lindberg (2020), where district nurses reported challenges with collaboration because of differing medical record systems used in hospital and primary care. Additionally, Drennan (2019) highlighted that under-investment in information technology was likely to contribute to inefficiencies with the district nursing service. Therefore, more robust communication pathways that endorse streamlined referral processes and sharing of information are recommended, alongside open and effective communication, collaboration and co-ordination within multidisciplinary teams (Young and Reid, 2021).

Participants also believed the factors influencing the embedding of the key worker role are multi-faceted in nature. These ranged from insufficient detail from the point of referral to key factors such as the lack of other support services. Similar issues have been reported throughout the UK (QNI, 2022) and are likely to influence the standard and quality of care delivered by teams. Hence, if the key worker role is to be enacted, consideration of policy and protocol in terms of improved standards of preparation and training is recommended.

Limitations

It should be noted that this study was carried out during a period of NHS workforce strikes that are founded on issues such as unsafe staffing levels across the NHS in the UK (Morgan, 2022). Therefore, it is recognised that emotions are likely to be heightened around workforce shortages that ultimately impact on patient safety, which are at the forefront of the challenges faced within healthcare teams (Royal College of Nursing, 2022). Moreover, this study does not aim to provide generalisable findings, rather it only presents an insight into the understanding among a small purposively selected sample of participants. Transferability to other countries may be limited as the role of the district nurse and the health care organisation may be different between countries.

Key points

- A nominated key worker is recommended in international guidelines and frameworks to co-ordinate a multidisciplinary and integrated palliative care approach for those with progressive and life limiting palliative conditions.
- A palliative care key worker is often identified to be the role of the district nurse within community based palliative care to improve access to palliative care services across healthcare interfaces.
- Clear roles and responsibilities of the palliative care key worker are often poorly defined and validated, resulting in lack of standardised practice within district nursing teams.
- Formal education and training for the palliative link worker is needed to ensure development and implementation of the role is inherent to the remit of district nurses.
- Development of succinct policies and guidelines which formalise the palliative key worker role implementation will be intrinsic to embedding the role within future practice.

Finally, the primary researcher (LMcD) of the study holds the district nurse specialist practice qualification and has previous experience of working in a district nursing team providing palliative care. While the researcher attempted to remain as reflective and reflexive as possible to ensure they did not lead or influence the participants during data collection, dynamisms in power shifts between the researcher and the participant may have influenced the data collection and analysis process. To ensure rigour, a second independent researcher was involved in the data analysis process (Johnson et al, 2020).

Conclusion

This qualitative study offers valuable insight into the understanding and perceptions of district nurse trainees who are based in district nursing teams regionally, with regard to the palliative care key worker role. However, there remain questions concerning the development and implementation of this role in practice. According to the participants, the findings are suggestive of opportunities to incorporate relevant support and education to facilitate the development and embedment of the key worker role. A review of resources, workforce capacity issues and implementation approaches are needed to ensure the role does not remain within the rhetoric of policy.

Author Contributions

All the authors, (LMcD and FH) have made substantive intellectual contributions to the manuscript. FH, contributed to the conception and design. LMcD led the data collection and both authors were involved in the data analysis. All authors contributed to drafting the manuscript, revising it critically for intellectual content and have given final approval of the version to be published.

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CPD reflective questions

- What are the benefits of formalised policies and protocols in relation to the palliative care key worker role?
- How can communication pathways be improved to facilitate the effectiveness of the key worker role within district nursing teams and across palliative care services?
- What aspects of education and training do you consider should be included to prepare the key worker to fulfil the role?
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