Roles and responsibilities of the community palliative care key worker: a scoping review

Hasson, F., Betts, M., Shannon, C., & Fee, A. (2022). Roles and responsibilities of the community palliative care key worker: a scoping review. *British Journal of Community Nursing*, *27*(8), 384-391. https://doi.org/10.12968/bjcn.2022.27.8.384

Published in:
British Journal of Community Nursing

Publication Status:
Published (in print/issue): 04/08/2022

DOI:
10.12968/bjcn.2022.27.8.384

Document Version
Author Accepted version

British Journal of Community Nursing

ROLE AND RESPONSIBILITIES OF THE COMMUNITY PALLIATIVE CARE KEY WORKER: A SCOPING REVIEW

--Manuscript Draft--

Manuscript Number:	bjcn.2022.0060R1
Full Title:	ROLE AND RESPONSIBILITIES OF THE COMMUNITY PALLIATIVE CARE KEY WORKER: A SCOPING REVIEW
Short Title:	Palliative care key worker
Article Type:	Research
Keywords:	keyworker; Palliative care; Community; scoping review; end of life
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Abstract:	The completion of a scoping review of the evidence relating to the role of the palliative care keyworker, which offers and insight into the present literature relating to the role and responsibilities. Whilst advocated in international and national policy, the evidence underpinning this role is lacking with only five empirical papers, two national and three internationals, adopting exploratory designs were retrieved. The review identified the need for the key worker role in palliative care however little consensus exists on who should adopt this role and their remit existed. Several implementation barriers were cited relating to communication and training. Further research on the development and implementation as well as consensus on the allocation of duties of the keyworker role would expand the existing evidence base.
Suggested Reviewers:	George Kernohan Professor of Health Technology, Ulster University - Belfast Campus wg.kernohan@ulster.ac.uk He was involved in the earliest work in this area with Dunne et al (2005)
Response to Reviewers:	SUMMARY OF REVISIONS Ref.: Ms. No. bjcn.2022.0060 ROLE AND RESPONSIBILITIES OF THE COMMUNITY PALLIATIVE CARE KEY WORKER: A SCOPING REVIEW British Journal of Community Nursing Reviewer #1: 1The article isn't clear whether this is related to children or adult patient key workers. But Table 1 defines professions related to children and not both. Is this purposeful? Thank you, the paper relates to the role of the key worker generically in palliative care

(adult or paediatric). Several examples of the variability of the key worker role are presented but these relate to adult and children i.e., District Nurse, GP, Mental health etc. In response the title of the paper has been altered to include adult and children.

Table 1 – Variance of key worker role across clinical settings for adult and children services

2What is the rationale to why articles are searched from >2003?
Thank you, the key worker was formally introduced in the UK, in 2004, therefore the year before this (2003) was selected as the starting point to ensure no evidence was missed. This rationale has been included in the paper. The following sentences have been added to the methodology section - Stage 2: identifying relevant studies.

In 2004 NICE 17 issued the first guidance for the key worker role in supportive and palliative are services for adults with cancer in the UK. Therefore the year before this (2003) was selected as the starting point to ensure no evidence was missed

Reviewer #2:
3It would be interesting to see what current practice hospice care facilities have in terms of keyworkers and also charities such as Macmillan and see what their strategy is (if one exists), to give a bit of a comparison.Thank you, the search did not uncover any empirical or grey literature on the keyworker from these organisations. Therefore, this point is outside the scope of this current study. However, the need for further research on the role allocation, implementation and effectiveness has already been reported.

4Also, the link between acute care and referral mechanisms to primary care to ascertain what exists and whether that is coherent across the UK or sporadic. Thank you, whilst this is an important, no evidence retrieved from the search process reported on this. Therefore, it is outside the scope of the findings of this evidence synthesis. However, this has been reflected in the need for more research.

5Possibly some figures as to how many people pass in acute care compared to in the community.Thank you, again this is outside of the scope of this review as the keyworker role is in place to work across systems and coordinate care. However, a reference has been added of the increasing demand for palliative care services internationally and nationally.

The palliative care sector is facing rising demands globally (Centeno & Arias-Casais 2019 and nationally (von Petersdorff et al 2021) for its services, however, to meet those demands there is the need for coordination.

Additional Information:	
Question	**Response**
Please enter the word count of your manuscript, **excluding references and tables**	2946

TITLE: ROLE AND RESPONSIBILITIES OF THE COMMUNITY PALLIATIVE CARE KEY WORKER: A SCOPING REVIEW

Running head: COMMUNITY PALLIATIVE CARE KEY WORKER

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Paper word count: 2946

ABSTRACT

The completion of a scoping review of the evidence relating to the role of the palliative care keyworker, which offers and insight into the present literature relating to the role and responsibilities. Whilst advocated in international and national policy, the evidence underpinning this role is lacking with only five empirical papers, two national and three internationals, adopting exploratory designs were retrieved. The review identified the need for the key worker role in palliative care however little consensus exists on who should adopt this role and their remit existed. Several implementation barriers were cited relating to communication and training. Further research on the development and implementation as well as consensus on the allocation of duties of the keyworker role would expand the existing evidence base.

Abstract word count: 124

Keywords: keyworker, palliative care, community , scoping review, end of life

KEY POINTS

- The key worker is described as a professional with responsibility for planning and co-ordinating care for patients who have been identified as requiring end of life care, aiming to maximise quality of life.
- This review highlights a lack of previous research in relation to roles and responsibilities of key workers in community-based palliative care.
- Although findings demonstrate that the role of key worker is advocated for continuity of care, uncertainty regarding who is best placed to adopt the role, and tasks involved in the role were evident.
- Barriers that underpin the effective implementation of the role within community based multidisciplinary palliative care teams were reported.
- Further research will allow exploration of the role of key worker and how the role is allocated, implemented, and gauged to be effective within health systems.

REFLECTIVE QUESTIONS

1. What are your thoughts, assumptions, and expectations about the keyworker role in palliative care?
2. What support mechanisms need to be in place to support this role in your practice?
3. How would a community palliative care keyworker impact upon your practice?

INTRODUCTION

Internationally, the role of the key worker is a fixture across health and social care systems (Brogaard et al, 2011, International Association for Hospice & Palliative Care 2919a). introduced to enhance patient centred care. Whilst first mentioned by the World Health Organisation (WHO) in 2016, there has been little evidence of this role being defined across the globe. Without standardisation, the title, role, and function vary according within and across countries and professions (Feuz 2014; Hull & Turton 2014). For example, in the United Kingdom (UK) variance of key worker role across clinical settings exist (see table 1).

<< *Please insert table 1 here*>>

The palliative care sector is facing rising demands globally (Centeno & Arias-Casais 2019 and nationally (von Petersdorff et al 2021) for its services, however, to meet those demands there is the need for coordination. Within palliative care the key worker is described as a professional with responsibility for planning and co-ordinating care for patients who have been identified as requiring end of life care, aiming to maximise quality of life (Palliative Care in Partnership 2017). Generally, based in the community care setting and are responsible for engaging with patients and their families whilst sharing information with the wider multidisciplinary team (Gold Standards Framework, 2009). They can also develop therapeutic relationships with the patient and their family to become an effective advocate before deterioration thus facilitating shared decision-making. This also allows the keyworker to network with other services (including voluntary) to help provide the tools for the best quality of life before death (Department of Health (DH) 2010; Health and Social Care Board 2017).

The concept of the key worker role is recognised in the UK through inclusion in policies and guidance (National Institute for Health and Care Excellence (NICE), 2004; DH, 2009; 2010; Department of Health, Social Services and Public Safety (DHSSPS), 2018). It was initially planned that different practitioners would be likely to perform the key worker role (NICE, 2004), but this proved challenging (Brogaard et al, 2011). However, nationally the district nurse as palliative care keyworker has been endorsed (DH 2010;2009; NICE, 2004; National Council for Palliative Care and Skills for Care, 2014) and it is recommended that every person in need of end-of-life care should have an identified key worker (DH, 2010). Despite some regional guidance existing advising how the implementation of the key worker role should look, no national guidance exists to cover the four areas of the UK (Ling et al, 2017). Consequently, a lack of interprofessional understanding regarding roles and abilities, ultimately has a negative impact on the provision of high-quality care for patients (Deshkulkarn, 2009) Recognition of the key worker role and what the expectations are, crucial to developing and fulfilling current policies. In light of this the aim of this current review was therefore to provide an overview of the existing literature on the role and responsibilities of a palliative care key worker.

METHOD

Scoping Review

Given the lack of existing systematic review of the evidence base and the wide remit of the study, a scoping review was considered the most suitable design(Arksey & O'Malley, 2005; Moher et al, 2009). The review was guided by Joanna Briggs Institute (2015) to ensure rigour and methodological frameworks (Arskey & O’Malley, 2005; Levac et al, 2010; Peters et al, 2015). The search was undertaken in accordance with the PRISMA reporting guidelines for scoping reviews (PRISMA-ScR) (Tricco et al, 2018). To further guide the search, process definitions (see table 2) were adhered to.

<< *Insert table 2 here*>>

Based on this information, two research questions were developed informed by the evidence base:

- What is the expected role of the palliative care key worker in palliative and end of life care?
- What are the responsibilities expected of the palliative care key worker?

Search strategy

In collaboration with the specialist librarian, the following academic databases were searched MEDLINE (via Ovid), Scopus and Web of Science from 2003- July 2021. In 2004 NICE, issued the first guidance for the key worker role in supportive and palliative care services for adults with cancer in the UK. Therefore the year before this (2003) was selected as the starting point to ensure no evidence was missed. In line with Joanna Briggs (2015- 27) the search terms were developed from a preliminary search two empirical databases (Medline and Scopus) and from input from experts in the area.   Terms were searched as both keywords in the title and/ or abstract and subject headings (i.e. MeSH) and truncated for variations in spelling (e.g., Nurs*) as appropriate. Boolean logic and operator (AND/OR) were also used to expand the search. See table 3 for key terms.

<<*Insert table 3 here*>>

Grey literature was also searched including, reference lists of papers found, Web of Science Conference Proceedings and organisation's websites including the Palliative Care Forum for

Northern Ireland, Nursing and Midwifery Council (UK) and Palliative Care Research Society UK and European Association of Palliative Care (EAPC) was completed.

All articles were subject to eligibility screening by two independent investigators (MB & FH). The following credibility criteria was formulated and used to determine what studies and evidence were eligible for inclusion in this review (see table 4).

<< *Insert table 4 here*>>

From the search a total of 34 articles were retrieved (see figure 1). Upon removal of duplicates this resulted in 13 articles, which were screened based on title and abstract. This process resulted in 5 articles subject to full text review.

<< *Insert Figure 1 PRISMA -ScR here*>>

Data extraction & analysis

An extraction form was developed to chart the data, based on the research questions (see table 5). As suggested by Levac et al, (2010), data was extracted independently by two investigators (MB & FH).

<< *Insert table 5here*>>

All papers were independently read and subject to thematic analysis using Braun and Clarke's, (2006) framework by the two authors (MB & FH). Key similarities and differences were categorized and developed into themes (Arskey & O’Malley, 2005; Levac et al, 2010) which helped to highlight gaps in the literature.

Finding’s overview

Of the five papers, two were undertaken in the UK (Dunne et al, 2005; Ling et al, 2017), whilst the remaining studies were international (Brogaard et al, 2011; van der Plas et al, 2017; Midlöv & Lindberg 2020). Two adopted a qualitative design (Dunne et al, 2005; Midlöv & Lindberg, 2020) and three, a quantitative approach (Ling et al, 2017; van der Plas et al, 2017; Brogaard et al, 2011. Dunne et al, (2005) undertook unstructured interviews guided by the Husserlian phenomenological approach. Midlöv and Lindberg (2020) conducted semi-structured interviews which were then analysed according to the qualitative content analysis methods. Brogarrd et al, (2011) used a validated instrument (EORTC QLQ C15 PAL) to assess views whilst Ling et al, (2017) and van der Plas et al, (2017) used unvalidated instruments. All studies used purposive sampling. Participant groups varied from registered nurses, (Dunne et al, 2005; van der Plas et al, 2017; Midlöv & Lindberg 2020) case managers, patients, and other staff (van der Plas et al, 2017; Ling et al, 2017; Brogaard et al, 2011). Sample sizes ranged from 12 to 183.

Reporting results

From the five papers reviewed, two themes were evident: 1.) Perceptions of the key worker role regarding palliative home care; 2.) Barriers to the implementation of the key worker role.

Theme 1: Perceptions of the key worker role regarding the provision of palliative home care

Studies highlighted views from patients, families and healthcare professionals regarding the function and impact of the key worker role on palliative home care. Uncertainty about the role, operationalisation of key worker, and differing views about who should occupy the role were evident in studies.

Although the key worker role was advocated as being beneficial for continuity of care in all studies, there was some lack of agreement about who would be ideally placed to adopt the role, or whether it should be defined as a separate role. Specific details on the role, responsibilities and core competencies of the key worker role were not reported. Rather, studies focused on who was, or who should be responsible for this position, and there was uncertainty about what the role entailed. For example, van der Plas et al, (2017) reported that in the Netherlands both the GP and district nurse occupied this role; in England it was the community nurse (Ling et al, 2017). Whilst Brogaard et al, (2011) reported differences of opinion between patients, relatives, and professionals about who was ideally suited to the role; and Dunne et al, (2005) reported that even though their study participants (district nurses) acted in the role of key worker they had not been formally designated as such.

In Denmark, Brogaard et al, (2011) emphasised the need to nominate a key worker to ensure clinical continuity of care for patients at the end of life. Results indicated that both GPs and community nurses viewed themselves as fulfilling the key worker role, and patients felt that GPs were best suited to the role. However, relatives believed they were best placed to be key worker. Brogaard et al, (2011) concluded that since there was a difference of opinion between healthcare professionals and patients/relatives about who should occupy the role of key worker, some professionals may have overestimated how much they personally co-ordinated patient care.

Similarly, differences in perspectives between clinical staff and patients regarding the key worker role were revealed in a study in the United Kingdom by Ling et al, (2017) In this study a non-validated questionnaire, with a non-purposive sample of patients (n=46) and community nurses (n=101) explored perspectives on the key worker's role within cancer care. Staff respondents viewed the term 'key worker' as a formalisation of existing working practices, potentially signifying a lack of awareness of the function of this role. On the other hand, patient participants reported that the role of key worker was 'highly valued'. However, findings of this study did not go as far as revealing if patient care would have been different if they had not been assigned a key worker.

In the Netherlands, van der Plas et al, (2017) explored the views of informal caregivers on the introduction of a case manager (a specialist palliative care nurse) to complement the existing care of a community nurse and a GP. Caregivers generally perceived this addition to their care team as beneficial particularly around the provision of specific knowledge of palliative care offered by the specialist palliative care nurse. However, authors emphasised that although the introduction of a case manager was valued, caregivers also needed a clear understanding of roles and responsibilities of each of the professionals involved.

In Northern Ireland, Dunne et al, (2005) explored the experiences of district nurses providing palliative care for cancer patients and their families. District nurses were described as dealing with practical elements of their usual role as well as overcoming challenges in liaison with other professionals, thus fulfilling a crucial care co-ordination role. Overcoming obstacles such as accessing out of hours support, and late referrals of patients to community palliative care teams meant that district nurses had to develop relationships and undertake care co-ordination between a range of health care professionals and patients/families. It was also reported that communicating the patient’s prognosis and dealing with the precarious position of providing care when the patient was not fully aware of their future could be problematic. This was further complicated by a lack of training in how to include children/adolescents into such communication.

Whilst dated Dunne et al, (2005) noted that currently, within their geographical location, the provision of palliative care was ‘disjointed’ and that this could be improved through the introduction of ‘one single person’ who could be responsible for overall co-ordination of care. The district nurse respondents in this study had not been identified as key workers despite other district nurses in neighbouring health trusts being designated this status. This potentially signified ambiguity about the perception of the role of key worker, and dissonance between policy and practice in this region. Dunne et al, (2005) recognised that although an integrated approach to care needed to be maintained, district nurses should be identified as the key workers within palliative home care thus improving standardisation of this role.

Theme 2: Barriers to the implementation of the key worker role

Although participants in selected studies understood the importance of care-coordination in palliative home care, issues around communication and training, and uncertainly around key worker role appeared to be barriers to implementation.

Ling et al, (2017) reported community nurses’ implementation of the key worker role had been communicated to them in an inconsistent manor, signifying a lack of standardisation and adherence to policy guidelines. This was further complicated by a lack of specific training and detail of the role in the clinical setting. Those who were allocated the role, did not see a difference in their existing role, nor did it impact on the time spent with patients, but did result in additional paperwork. More recently Midlöv and Lindberg (2020) reported the experiences of district nurses in providing palliative home care highlighting the complexity of the role and the need for collaboration. Findings of this study revealed the complexities of the care co-ordination role, and district nurses reported that additional resources, greater access to the palliative care team and continuous training in palliative care would improve the provision of palliative home care and care-ordination.

Findings of Brogaard et al, (2011) indicated disagreement between nurses, doctors, patients and relatives about the key worker concept. This was the only study where patients and carers viewed themselves as key worker, over and above doctors and nurses. Also, GP's and community nurses viewed themselves as the key worker. Although this may signify confusion about the role of key worker, study authors assert that the reason for the difference of opinion is more likely to be '*real disagreement concerning role and task distribution'* of the key worker. In light of this calls for explicit communication on each contributor's role in palliative home care was recommended (Brogaard et al, 2011; van der Plas et al, 2017) thus helping to ensure effective palliative care co-ordination may be achieved.

DISCUSSION

This review sought to provide an overview of existing literature on the role and responsibilities of the palliative care key worker. Despite being advocated in policy and guidelines (DHSSPS 2018; DH 2009; NICE, 2004) the palliative care key worker is largely invisible in the empirical literature, with only five studies retrieved. This represents a key lack of understanding of the impact of the role on patient and caregivers' journey at the end of life. Unsurprisingly all of the studies established the need for further research into the role of the palliative care key worker.

Two studies explored the experience and views of those who deliver the role in practice, (Dunne et al, 2005; Midlöv & Lindberg, 2020), whilst remaining studies concentrated on patients, relatives, or other professionals (Ling et al, 2017 Brogaard et al, 2011). No study identified who was best placed to fulfil the role of the key worker in palliative care, which reflects the complexity of providing coordinated care across generalist and specialist providers and multi-disciplinary teams. Care coordination has been viewed as vital for patients' continuity of care at the end of life (Schultz et al, 2013), with key workers being an important component of such care (NICE, 2004; Boyd et al, 2009), yet results of the current review suggest uncertainty and lack of standardization around the key worker role within palliative home care.

Findings of the current review highlighted barriers to the implementation of the key worker role. Specifically: training, education, and clarification of the role. Feuz (2014) found that interdisciplinary collaboration was key to the provision of high-quality effective palliative care, however physicians are usually considered to be the ultimate decision makers (Bélanger et al, 2014). Feuz (2014) asserts that key workers are ideally placed to overcome professional culture barriers through facilitating improved communication within the interdisciplinary team. However, as reflected in our findings, lack of clarity around the role, and ineffective communication leading to mis-matched expectations, and lack of training for the role is often experienced within interdisciplinary palliative care teams, potentially leading to a reluctance to implement the role in a standardised way.

All selected studies discussed the community nurse within a vital care co-ordination role, but none established how the key worker role could be amalgamated into the role of the district nurse more fluently. Specialist education required to undertake the key worker role was also not deeply explored. The role needs to be valued by those who will be delivering this patient-centred care, therefore more attention is required in this area.

Given the dearth of existing literature on the palliative care key worker role, the findings of this scoping review highlight gaps that exist in relation to the utilisation, implementation and effectiveness of this role in clinical practice. Included studies are generally small scale with two based on international findings, limiting the generalisability of the findings. Findings from the studies are mainly inconclusive regarding the role and responsibilities of the palliative care key worker. This scoping review supports the claim in previous research (Feuz, 2014) and editorial pieces (Berry, 2015) that gaps in understanding exist on the keyworker’s role in palliative care. Further exploration and research are required to establish the role of key worker and how the role is allocated, implemented, and gauged to be effective within health systems.

CONCLUSION

Review findings indicate a dearth of research and understanding of how the palliative care keyworker role is operationalized in practice. The results highlight that the role was advocated for continuity of care, however uncertainty regarding who should adopt this role was evident, and barriers underpinning the implementation of the role in practice were reported. Further research is warranted to establish the role of key worker and how the role is allocated, implemented, and gauged to be effective within health systems. This is important in order to improve our understanding about how the key worker role can be more effectively translated from policy to practice within a palliative home care setting.

Author Contributions

All the authors, (FH, MB, CS, AF) have made substantive intellectual contributions to the manuscript. FH, MB, and CS contributed to the conception and design. FH and MB were involved in searching and selection of the literature, extraction of data, and 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.

Declaration of interest: none

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Table 1 – Variance of key worker role across clinical settings for adult and children services

Profession	**Key worker role**
Social worker	Trip et al, (2016) showed that key workers could be support workers, supporting people with intellectual disabilities to self-manage their diabetes and were not required to be registered nurses to fulfil the role. They were following established role regimes provided by district nurses.
Specialist paediatric oncology nurse	Support children and their families. Hull and Turton (2014) required the role to be further defined.
General Practitioners	Brogaard at al, (2011) found a difference in opinion as to whom should take on the role of key worker in the primary care setting. Families felt that they could take on this role.
Mental health nurse	McCombe et al, (2019) found that the feasibility of a key worker in patients with a mental health condition, enhanced physical health through better interaction between primary and secondary care.
Psychologist	Identified in Australia by Davis et al, (2019) to work within paediatric disability teams – the key worker role is geared towards promoting parents' mental health and wellbeing.
District nurse	Identified as ideal to attain the key worker role – establishing care that is co-ordinated and person-centred to reflect the client's individual needs (DHSSPS 2018).

Table 2: Definitions of key terms

Term	Definition
Role	It is recognised that the concept role and responsibility may overlap therefore we defined a role as the overarching nature of the key worker's function.
Responsibility	Whilst a responsibility refers to the specific tasks they are required to undertake.
Palliative care	For the purpose of this study, the World Health Organisation (WHO) (2016) definition of palliative care will be adopted; "*an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"* (p.7).
District Nurse (also referred to as community nurse)	District nurse is defined as "*a registered nurse with a graduate level education possessing a district nursing specialist practitioner qualification recordable with the Nursing and Midwifery Council (NMC)*" (DHSSPS, 2018, p10.

Table 3: Search terms

1	*Key worker*: Key workers, link worker, support worker, case management, case manager.
2	*Palliative care*: Care of dying, Care of the dying, Dying, Edge of life, End of life, End-of-life care, Hospice care, Palliative, Palliative care services, Palliative therapy, Supportive care service, Support care, Supportive care, Terminal care
3	*Community nurse*: District nurse, District nur*, community health nurs*, community healthcare nurse, community nurs*, named nurs*

Table 4: Inclusion & Exclusion criteria

Inclusion	Exclusion
April 2003 – July 2021	Papers published before 2003
Community care setting	Acute care settings/ community hospital setting
Papers to be written in English.	Non-English documents
Quantitative, qualitative, or mixed method research based on UK and European sites	Editorials, commentaries, case reviews,
Studies that have focused on the community nurse key worker within palliative care.	Study which did not focus on the community nurse keyworker role

Table 5: Data extraction form

Author, date & country	**Aim**	**Design**	**Method**	**Sample**	**Findings (role and responsibilities)**	**Limitations**
Dunne et al (2005) Northern Ireland	To explore district nurses' experiences of providing palliative care for patients with cancer and their families.	Qualitative design. Unstructured interviews.	Husserlian phenomenological approach. Unstructured interviews. Colaizii's seven stages of data analysis used to interpret data.	Purposive sample of participants who had experienced the phenomenon. Participants were registered nurses with at least one year's experience working in a district nursing team. Caseload	District nurses were unaware that they were recommended as key worker. they provided palliative care to patients with an array of complex conditions. Their experiences of providing this	Only females involved recruited. Transferability of the findings of the study should be considered. Study did not include all life-limiting diseases.

				had to have 20% of patients requiring palliative care. 125 participants invited to take part – 32 did not reply, 30 declined invitation, 38 did not meet the sampling criteria. 25 district nurses included in the study.	care was challenging. The study identified the district nurse to be best placed as key workers in palliative care.	

Broggard et al (2011) Denmark	Exploration of who takes on the role of key worker and who patients, families and primary care professionals believe should hold the role.	Quantitative mixed. Mixed methods design using structured interviews and questionnaire study.	Structured interviews with end stage cancer patients. EORTC QLQ C15-PAL themes identified. Questionnaires to relatives and healthcare professionals. To describe participants' views, frequencies and percentages were calculated. Kappa	Adults with advanced, terminal cancer. Patients excluded if cognitively impaired. Patients were recruited prior hospital discharge following the inclusion criteria and also from primary care teams. 160 patients approached and a	There is no one person allocated the key worker role, with patients, relatives and professionals viewed themselves as such. The study found the GP as the ideal key worker.	Estimates were made of representativeness. 29% of interviews took place in the hospital setting prior to discharge. Hospital staff selected participants based on set criteria, there may have been selection bias in this process as the more vulnerable were

			coefficients used. Data analysed using STATA.	total of 96 adults recruited.		not invited to participate. Excluded patients may have had the most complex symptoms. Those discharged to hospice and nursing home were excluded.
Van der Plas et al (2017) Netherlands	The views of informal caregivers regarding the volume of	Quantitative design using questionnaires.	Case managers and a relative of the patient were both sent questionnaires 2	726 identified as possible participants for study and sent questionnaires.	The range of professionals included in providing care was appropriate.	Only a 25% response rate. Response could be altered due to the level of quality

	professionals involved in providing primary palliative care.		months following the patient’s death. Analyses were performed using SPSS and IBM statistics.	183 questionnaires returned. 35% male 65% female.	The case manager gave appropriate information more than the primary care team. Case managers spent more time with patients, providing reassurance to relatives. Involvement of a case manager should be promoted at an early stage.	palliative care received. Partners of patients gave more positive responses than that of the children of patients. Results could be biased when patients were visited more frequently from the case manager than those who

						only had received 1 visit. Specific questions omitted regarding the community nurse were assumed that there was no nurse involved (31%).
Ling et al (2017) England (UK)	Patient and staff perspectives on the role of key workers in cancer care.	Quantitative design. Questionnaire.	Structured questionnaires for both patients and staff.	204 questionnaires sent to clinical nurse cancer	Perspectives on the role differed between the nurse and the patient. Patients were	Only 2 nurse participants were male. Low response rate from patients.

			Analyses were performed using SPSS.	specialists – 101 completed. 200 questionnaires sent to patients undergoing cancer care – 46 completed.	keen to have the same key worker throughout their illness. This was not the case for staff, 28% felt thar the same key worker should not stay with the patient throughout their journey. Staff were less keen to undertake the role as only 7.9% had specific	Possible sample bias as the nurse requested patients to participate. Study only focused on patients with cancer. Study based in secondary care.

					key worker training.	
Midlov, and Lindberg, (2020) Sweden	To highlight district nurses' experiences of providing palliative care in the home	Qualitative design. Semi-structured interviews.	Semi-structured interviews with 12 district nurses. These interviews were analysed according to the qualitative content analysis method	12 district nurses (three men and nine women) with a specialist nursing education who had been working as district nurses for between 7 and 34 years (mean 21 years). The nurses had worked in home care for between 5 and 34	The three main findings of the study were that collaboration with others was deemed as being essential, providing palliative care in the home is emotionally demanding but rewarding, and	Small study with just 12 participants. The researchers had no experience of district nursing and noted that interview quality is dependent on knowledge and approach – they stated they found it difficult to avoid leading questions

				years (mean 21 years), and this included experience of providing palliative care in the home and 8 of the 12 district nurses had previous education in palliative care. Participants were recruited through contact with their	the work is additionally time and expertise consuming. District nurses would like more resources and organisational changes such as access to doctors and a palliative home care team who only work with these patients as this would benefit	so the openness and depth of the interview may have been affected.

				managers and the aim was to recruit participants who shared some characteristic features representing what was required for the study.	both district nurses and patients.	

Figure 1: PRISMA-ScR Flow diagram

PRISMA 2009 Flow Diagram