

Gaps in understanding the experiences of homecare workers providing care for people with dementia up to the end of life: A systematic review

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## **Abstract**

This systematic review of the literature explores the perspectives and experiences of homecare workers providing care for people with dementia living at home up to the end of life. A search of major English language databases in 2016 identified 378 studies on the topic, of which 12 met the inclusion criteria. No empirical research was identified that specifically addressed the research question. However, synthesis of the findings from the broader literature revealed three overarching themes: value of job role, emotional labour, and poor information and communication. The role of homecare workers supporting a person with dementia upto the end of life remains under-researched, with unmet needs for informational, technical and emotional support reported. The effective components of training and support are yet to be identified.

**Keywords: homecare, home health aide, dementia, end of life, social care, community care**

## **Introduction**

High quality end of life care for people living in their homes is increasingly advocated by policymakers and dementia care stakeholders (Alzheimer's Society, 2011; Department of Health 2008, 2013). Almost half a million people in England (470,000) receive local authority funded homecare services of whom 80 percent are aged 65 years or over (Health and Social Care Information Centre, 2014). Large numbers also pay for homecare services themselves. Homecare services provide practical and emotional support to people who need help to continue living in their own homes. Ideally they facilitate choice whilst maintaining safety in a community setting (Royal Pharmaceutical Society, 2014), enabling people to remain independent in their own home for as long as possible. Homecare is viewed as an optimum way to maintain the quality of life for people with dementia wishing to live and die in their own homes (Bökberg et al., 2015; Clarkson et al., 2016).

There is much disparity around the terminology of homecare working as various terms are used globally, such as in-home assistant, personal care aide, personal care assistant/attendant, home care aide, home care assistant, home health aide, direct care worker, support worker (Devlin & McIlfratrick, 2009). For the purpose of this review, we use the United Kingdom (UK) term "homecare worker". Their employment or formal contractual status distinguishes them from informal carers, such as family members, volunteers or friends. Globally, homecare work may encompass tasks ranging from domestic cleaning (Arts, Kerkstra, van Der Zee & Huyer, 1999) to providing more intimate personal hygiene care (Stacey, 2005). Many homecare workers undertake a range of essential practical and personal care tasks for people with dementia living in their own homes, including support with activities of daily living, household tasks, or short breaks, medicine management, and monitoring (Morgan et

al. 2016; UNISON, 2013). They may also provide emotional and psychological support, both to the care recipient and family carers (Piercy, 2000).

Homecare workers are often paid close to the National Minimum Wage and sometimes less in England (Kingsmill, 2014; Koehler, 2014), and other practices, such as ‘zero hour contracts’ (non-guaranteed hours of work) and non-payment of travel time between appointments are commonplace (Kingsmill, 2014). Additionally, the practice of ‘call cramming’ (where homecare workers are routinely given too many visits too close together) means homecare workers may lack the time to provide sufficient care (ibid). The trade union UNISON reported that workers often refuse to leave early but stay to provide the level of care they believe is necessary in their own time and at personal cost (UNISON, 2013). Homecare workers also work in isolation, often not having any interaction with other workers, and this isolation may negatively impact on their stress levels, morale and ability to develop and progress in their role. These precarious working conditions result in high levels of staff turnover (Equality and Human Rights Commission, 2011) and may be unsettling for clients who have to adjust to new faces. Overall, the sector experiences difficulties in attracting and retaining a skilled, experienced workforce that can meet the needs of people requiring care and support.

A skilled and experienced workforce is paramount considering that homecare workers provide the majority of non-clinical care for older people with dementia (Hussein & Manthorpe, 2012). In 2015, there were 850,000 people living with dementia in the UK with 67% living at home (Alzheimer’s Society & Marie Curie Cancer Care, 2014). Even though the majority of older people with dementia are more likely to die in care homes than at home (see Murtagh et al. 2012), most people with dementia wish to live in their own homes for as long as possible (Davies & Higginson, 2004; Department of Health, 2013; Gott, Seymour,

Bellamy, Clark, & Ahmedzai, 2004). Although not everyone will choose to die at home, current government policy in England encourages people to ‘die in the place of their choice’ (Department of Health, 2013; Leadership Alliance for the Care of Dying People, 2014). It is reported that most people would choose to die in their own homes, with support in place to make their last days peaceful and pain-free (Department of Health, 2013). The proportion of people in England dying at home or in care homes rather than in hospital increased from 38% in 2008 to 44% in 2012 (National End of Life Care Intelligence Network, 2013). Thus, with the emphasis on living and dying at home, there is increasing need for families and homecare workers to care for older people with dementia as death approaches. While people dying at home are likely to receive NHS clinical services (from General Practitioners, community nurses and palliative care teams) they may also be supported by homecare workers. However, while many studies have focused on clinical and nursing care in the context of caring for people with dementia at the end of life at home (Alzheimer’s Society, 2011; Marie Curie, 2009), the role of homecare workers has not commanded substantial research interest.

Dementia’s unpredictable trajectory often makes it difficult for health and social care practitioners to tell when the end of life is approaching (Moriarty, Rutter, Ross, & Holmes, 2012). In the context of social care, traditional clinical and palliative definitions of end of life (General Medical Council, 2010) may not apply to the same degree and end of life may rest on a more fluid definition (Goodman, Froggatt, & Mathie, 2012; Vandrevalla, Samsi, & Manthorpe, 2015). Therefore, for the purposes of this review, we did not adopt a narrow definition of end of life as being the last 12 months or last few weeks of life, but instead, define this as the last years of life. There is growing evidence that people with dementia are not being identified for specialist end of life care, and that they have less access to, and receive poorer quality care than people with other terminal illnesses (Alzheimer’s Society & Marie Curie Cancer Care, 2014; Raymond et al. 2014) . UK studies have suggested that fewer

than 20% of those with frailty or dementia are benefitting from palliative care (Alzheimer's Society & Marie Curie Cancer Care, 2014; Sampson et al. 2006). Even with input from palliative care services, people with dementia who wish to spend their last days of life at home are still likely to be cared for by their families with the assistance of homecare workers. Little is known about the attitudes, experiences and challenges of homecare workers when providing care to those with dementia who are at end of life. Overall homecare workers sometimes have reported that their work with people with dementia presents particular problems, compounded by limited dementia-specific training (All-Party Parliamentary Group on Dementia, 2009; Alzheimer's Society, 2011; Hussein & Manthorpe, 2012). Furthermore, the homecare workforce is characterised by lack of supervision, support and training (Rubery, Grimshaw, Hebson, & Ugarte, 2015; Westerberg & Tafvelin, 2014). Against this backdrop, we aimed to review existing evidence in order to address the following research question: What are the gaps in understanding of the experiences of homecare workers providing care upto the end of life for people with dementia?

## **Methods**

A systematic literature search was undertaken of research exploring the perspectives and experiences of homecare workers providing care at the end of life to people with dementia. In January 2016, we searched eight electronic databases including literature from social sciences [ASSIA and Sociological Abstracts], nursing [CINAHL], biomedical sciences [EMBASE], multidisciplinary research forums [SCOPUS and Web of Science], and healthcare systematic reviews [Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials]. Key concepts in the review question informed the search strategy used for these databases. The following words were used in combination to search each electronic

database: “homecare worker” and “dementia or Alzheimer’s” and “end of life”, “death” or “dying”, and “palliative care”. Additionally, common acronyms for the term homecare worker were used in searching the literature, including “home care aide”, “home health aide”, “personal care aide/assistant/attendant”, “direct care worker”, “domiciliary worker and support worker” (see Table 1 for a summary of search terms). Our focus on homecare excluded care provided in long-term care facilities and that provided by family carers or volunteers.

(Insert Table 1 here)

### **Inclusion criteria**

Searches were restricted to English language sources, including international literature published in 1995 or later. Studies were selected for inclusion if they met the criteria of focusing on homecare workers providing care for people with dementia and/or providing end of life care. A total of 378 studies were identified of which 12 met the inclusion criteria for the review (See Figure 1 PRISMA flow diagram).

(Insert figure 1 here)

### **Study selection and data extraction**

The assessment process was undertaken in two phases. First, one reviewer (VD) removed duplicates and discarded 224 publications deemed irrelevant on the basis of title and/or abstract. From the refined list of 109 citations, two reviewers (VD and RA) independently assessed full-text articles for inclusion if they met the necessary criteria. Ninety-seven articles were excluded with reasons identified and categorised. Full text articles were excluded if: they did not include homecare workers [26], and dementia or end-of-life care [58]; if they were strictly policy related [8] or focused on clinical practice [5]. Both empirical studies and review papers were included in the selection. If studies involved several health and care

professionals, only those papers that presented the results separately for each profession/job role were included.

Inter-rater agreement was obtained by the two reviewers randomly selecting and independently rating 10 papers assessed as not meeting inclusion criteria by the other reviewer, 90% inter-rater agreement was achieved. Discrepancies between reviewers were resolved through consensus and through consultation with remaining reviewers (TV and JM). In addition to the above search, individual searches on key authors in the field were carried out and references from seminal articles were followed up. Twelve papers were included in the qualitative synthesis (see Figure 1 PRISMA flow diagram). In phase two, a specific data extraction form was developed for the screening appraisal to ensure studies met the inclusion criteria. The 12 papers were subjected to further classification and assessment. For each of the 12 papers, four reviewers independently extracted information on three key points: the focus of the study, methodology and sample, and key findings (see Table 1). Based on the small number of papers, no quality of assessment of the studies included was conducted as they covered a great diversity of method designs and foci of interest. Comments on overall quality of the papers are made in the discussion. All papers comprising the foundation of this systematic review were read repeatedly to synthesise overarching themes.

### **Data Synthesis**

Data were synthesised across common key themes found. Papers included studies from Israel (Ben-Arie & Lecovich, 2014), Japan (Igarashi et al., 2015), United States (US) (Boerner et al. 2015; Riesenbeck et al. 2015; Butler, 2009), Canada (Morgan et al. 2016), Belgium (Roelands et al. 2005) and the UK (Dawson et al. 2015; Devlin & McIlfatrick, 2009; 2010; Ryan et al. 2004; Herber & Johnston, 2013). Papers had been published between 2004 and 2015, and considered homecare not family carers/caregivers or nursing professionals within



the homecare context. Empirical research included quantitative and qualitative methodologies, including postal survey, questionnaires, face-to-face interviews and focus groups.

## **Findings**

### *Characteristics of study papers*

Little literature was found focusing specifically on homecare workers providing care for people with dementia at end of life. Only one recent paper, published in the US, briefly acknowledged the increasing importance of the work of homecare workers in providing end of life care for people with dementia living in the community (Dawson et al. 2015).

Moreover, this paper was not empirical research but a review of the literature on community-based dementia care. Another five papers addressed the subject of homecare workers providing care for people with dementia living at home. They focused on job satisfaction (Ryan et al. 2004) and dissatisfaction (Ben-Arie & Lecovich, 2014), the experiences of older homecare workers (Butler, 2009), the counselling role of homecare workers (Roelands et al. 2005), and the frequency and competence of dementia-related tasks and continuing education priorities of homecare workers (Morgan et al. 2016). Six papers addressed homecare workers and end of life care (not exclusively focusing on work with people with dementia at the end of life), of which two concentrated on coping with client death and grief (Boerner et al. 2015; Riesenbeck et al. 2015), two comprised a literature review of the role of homecare workers in palliative and end of life care (Devlin & McIlfatrick, 2009; Herber & Johnston, 2013), and two reported empirical research on the subject (Devlin & McIlfatrick, 2010; Igarashi et al., 2015).

Five studies used quantitative research methods with samples ranging from 41-601 participants (Ben-Arie & Lecovich, 2014; Boerner et al. 2015; Igarashi et al., 2015; Morgan

et al. 2016; Roelands et al. 2005). Three studies used qualitative research methods, with samples ranging from 7 to 80 homecare workers (Butler, 2009; Riesenbeck et al. 2015; Ryan et al. 2004). A mixed methods research design including a cross-sectional survey of 69 homecare workers and a focus group of 6 palliative care nurses was employed by Devlin and McIlfatrick (2010). Lastly, three papers were systematic literature reviews, one focusing on homecare workers and dementia (Dawson et al., 2015) and two on homecare workers and end of life care (Devlin & McIlfatrick, 2009; Herber & Johnston, 2013). Studies with quantitative designs seemed to stress clients' instrumental and functional disabilities and the needs of homecare workers, while those using qualitative methods focused more on the caring relationships and support needs of homecare workers in these roles.

### *Themes in the literature*

Three main themes were identified during data synthesis (Table 2). Table 3 provides an overview of the 12 papers included in the review, listed in alphabetical order.

(Insert Table 2 and Table 3 here)

### **A. Value of job role**

Based on the findings from ten papers, homecare workers felt that the lack of clarity of their job role, doubts about being a contributing team member and views on their own remuneration may lead them to question the value of their work and the contributions they make to the care of people with dementia dying at home.

#### *A1. Role ambiguity and lack of role validation*

Research has begun to highlight the substantial contribution that homecare workers make towards meeting not only the needs of people with dementia at end of life but also their families (Dawson et al. 2015). However, their contributions to caring for people dying at

home may be overshadowed by the ambiguity of their role and their unmet need for preparation and support in providing care at the end of life (Devlin & McIlfatrick, 2009). Misunderstandings of the role of homecare workers have been described by older people, their family members, and by health care professionals (Devlin & McIlfatrick, 2009). Greater attention to clarifying the roles and confirming responsibilities for homecare workers may improve their recognition and experience, validate their contribution to end of life care within multidisciplinary team working, and distinguish essential training and support needs (Butler 2009; Devlin & McIlfatrick, 2009, 2010). According to Morgan et al. (2016), one challenge reported by the homecare workers they interviewed was their feeling of lack of competence in discussing the behavioural changes associated with dementia with family members. For some, feelings of inclusion or engagement in the family unit was a major contributor of job satisfaction (Ryan et al. 2004), yet for those who did not feel so included, the impact of ambiguity and potential conflict remains unclear.

#### *A2. Feeling part of a team*

Alongside role ambiguity or confusion, homecare workers valued feeling part of a team member with healthcare professionals, and described honest communication as suggestive of such team work. Open communication with the healthcare team about their client's symptoms, changes in physical or mental abilities, identifying someone was in pain, and how to provide comfort were deemed essential to meeting a client's needs (Devlin & McIlfatrick, 2009) and were considered helpful in enabling homecare workers to anticipate a client's death. Additionally, effective communication with the multidisciplinary healthcare team enhanced homecare workers' sense of purpose, perception of being part of a team and contributed to job satisfaction (Ryan et al. 2004). Liaison with senior colleagues and homecare supervisors may also enhance workers' knowledge and competence and improve the quality of life for people with dementia (Ryan et al. 2004). The organisational ethos of the

homecare service, including close interpersonal relationships and good communication between managers and homecare workers, was said in one study to contribute to staff perceptions of being supported, recognised and valued (Ryan et al. 2004).

### *A3. Remuneration*

In spite of difficulties, homecare workers have reported their work as rewarding (Butler, 2009) and contributing towards the quality of life of the dying person (Ryan et al, 2004), which can, in some cases, offset their under-valued and lowly paid role (Ben-Arie & Lecovich, 2014). However, when faced with greater work demands, such as caring for a substantially cognitively impaired client, some homecare workers expected more remuneration in two studies (Ben-Arie & Lecovich, 2014; Butler, 2009). Evidence of low pay in this line of work is not a new finding, yet there is consistent mention of the need to improve wages and recognise the value of care work (Butler, 2009).

## **B. Emotional labour**

While the physical work of homecare can be strenuous (Butler, 2009), there is some evidence that homecare workers also need preparation for and support to cope with the emotional labour of providing end of life care (Igarashi et al. 2015). Despite a total of 12 articles exploring the impact on homecare workers providing care for people with dementia or end of life care, few explored the subjective emotional impact of this work (Devlin & McIlfatrick, 2009; Herber & Johnston, 2013).

### *B1. Dementia-related work stress*

One study found that homecare workers caring for individuals with memory impairment experienced higher levels of work stress compared to those caring for functionally able clients (Ben-Arie & Lecovich, 2014). This study also found that the more the homecare worker felt disturbed by a care recipient's cognitive and behavioural problems, the more

dissatisfied they felt with their job. When poor quality relationships with care recipients existed and higher levels of work efforts were frequently exerted, this could often become a source of job dissatisfaction (ibid). Yet to what extent these factors were causal or maintained over the long term is unknown. Furthermore, the impact of emotional investment involved in the establishment of relationships with clients who are significantly cognitively impaired remains uncertain (ibid). This may be of particular importance when the development of relationships is stated to be a primary benefit of the job (Butler, 2009). Providing extra time to allow relationships to form could reduce intention to leave (Butler, 2009), but of course incurs costs and may threaten the viability of the care provider. Limited skills in dementia care may also contribute to job strain (Ben-Arie & Lecovoch, 2014).

### *B2. Emotional strain related to end of life care*

The emotional labour of care work means that important relationships between homecare worker and client are sometimes formed (Butler, 2009; Herber & Johnston, 2013). When such close relationships were established, often over a period of time, grief was sometimes experienced more intensely by the homecare worker when their client died, akin for some to family bereavement (Boerner et al. 2015). Despite this, ambiguity around how the construct of grief is interpreted by homecare workers (Boerner et al. 2015) leaves a gap in knowledge about the difficulties of grief and coping in this line of work and the psychological burden this may incur (Devlin & McIlpatrick, 2010). Little attention has been paid to homecare workers' experiences of client death although there are suggestions that when a homecare worker is unprepared for this death, there is risk of heightened grief (Riesenbeck et al. 2015).

### *B3. Limited emotional support*

Informational, technical and emotional preparation were broadly recognised as unmet needs among the homecare workforce (Boerner et al. 2015; Devlin & McIlpatrick, 2009). Effective

emotional support acknowledges, legitimises and contextualises the feelings and perspectives of another person. A common recommendation from the studies reviewed was that homecare workers providing care for a person with dementia as they approach the end of life need not only the knowledge and skills necessary to provide effective care but also the informational, functional and emotional support to underpin their role. Little is known about how homecare managers and supervisors perceive and provide emotional support to homecare staff caring for clients with dementia at the end of life.

### **C. Limited preparation**

#### *C1. Limited client information to prepare them for the role*

Detailed information about the client, their wishes and preferences, as well as respectful, clear communication with family members, were perceived desirable by homecare workers to prepare them for their jobs (Roelands et al. 2005). Preparation was described in many ways including being given a clear understanding of the client's condition, care needs (Riesenbeck et al. 2015) and end of life preferences (Dawson et al. 2015). Limited information may make it difficult for a homecare worker to provide the right type or amount of care. In a US study exploring grief and preparedness for a client's death among 80 homecare workers (home health aides), two-fifths reported feeling 'not at all' prepared for their client's death either emotionally or in terms of information about their client's condition (Boerner et al. 2015). Acquiring information through ongoing communication with the healthcare team about symptoms, changes in physical or mental abilities, pain, and how to provide comfort was deemed essential for meeting the client's needs (Devlin & McIlfatrick, 2009) and was considered helpful in enabling homecare workers to prepare for and anticipate a client's death. As noted in relationship to team working, good channels of communication with the multidisciplinary healthcare team providing end of life care enhanced homecare workers'

sense of purpose, perception of being part of a team and contributed to job satisfaction (Ryan et al. 2004).

### *C2. Need for dementia-specific end of life training*

Most of the articles reviewed argued that homecare workers need more training specific to dementia and end of life care (Ben-Arie & Lecovich, 2014; Boerner et al. 2015; Butler, 2009; Dawson et al. 2015; Devlin & McIlfatrick, 2009; Heber & Johnston, 2013; Roelands et al. 2005). Enhancing homecare workers' knowledge and competence through training and continuing education may improve the quality of care they provide for people with dementia (Morgan et al. 2016). Additionally, skills in end of life care may enable homecare workers to provide better care and prepare them for client death (Boerner et al. 2015). However, the components of training for homecare workers providing care at the end of life remain vague and undefined. Moreover, training skills and credentials alone may not equate to experiential competence. The perceptions of training, competence and experiences of homecare workers in this role are missing from the evidence base.

## **Discussion**

This review of 12 papers was undertaken to identify gaps in current understanding of the experiences of homecare workers providing care upto the end of life for people with dementia. Overall, while some articles were found addressing homecare workers' experiences caring for people with dementia and other articles explored homecare workers' experiences caring for people upto the end of life, none addressed the overlap of the two experiences.

### *Role ambiguity*

The role of homecare workers is assumed to be physically, psychologically and socially demanding (Ben-Arie & Lecovich, 2014; Devlin & McIlfatrick, 2009), yet research reports some blurring in the roles of homecare workers at the end of life (Devlin & McIlfatrick,

2010; Herber & Johnston, 2013). This may be because homecare workers are already supporting persons with dementia prior to the end of life, and their role gradually adapts to new tasks and the presence of other professionals in the home setting. Others, however, may see their role as tightly prescribed, highlighting that because homecare workers are not professionally qualified and have low status, their role is marginal or regarded as non-skilled.

With increases in the numbers of people with dementia wishing to die at home, where possible and when supported by their family carers, and continuing policy drives to enable people to die in their place of choice, the role of the homecare worker is likely to expand. The current review makes an important contribution by highlighting the gaps in the evidence base while addressing the question of how homecare workers provide care for people with dementia up to the end of life and their experiences of doing so. Significant gaps in homecare workers' support and training, and the stress of the work and its emotional labour may need to be better acknowledged. However, the current review fails to reveal whether homecare workers view their roles as salient and valuable in supporting death at home, and, if so, in what respects.

Dawson and colleagues (2015) argued that the current weakness in the evidence base about homecare working with people with dementia presents challenges in designing better community-based care. This is further exacerbated by a lack of research about this area of homecare working and end of life care (Devlin & McIlfatrick, 2009). A clear understanding of the roles and responsibilities of homecare workers at end of life for a person with dementia dying at home may help diminish experiences of frustration and stress that result if the worker's status is unclear.

#### *Impact of emotional labour*



Research is also needed into the psychological burden of care for homecare workers (Devlin & McIlfatrick, 2010). In the absence of any evidence on dementia-specific end of life attitudes and experiences of homecare workers, and in acknowledgement that people may die *with* dementia or *from* dementia, the current review scoped the literature relevant to end of life experiences of homecare workers across other long-term conditions. It is interesting to note that a very limited evidence base exists on the views and experiences of homecare workers caring for any clients up to the end of life.

Much has been written about the emotional labour of nursing (Gray, 2009; McVicar, 2003), as well as emotional labour within care homes (Eaton, 2000; Vandrevalla et al., 2016). However, little has been studied in respect of homecare. Other professionals working within palliative or end of life care are often reported to be at risk of high stress and burnout (Hill et al. 2016). Furthermore, those who find their work meaningful, rewarding or akin to a calling are often described as being at risk of being overly consumed by their work, making disengagement or ‘switching-off’ difficult (Clinton et al. 2016; Mainemelis, 2001). When the care sector relies on empathy and compassion (Piercy, 2000) yet in some areas zero-hour contracts and call-cramming are commonplace (Kingsmill, 2014), the potential for role conflict and worker exploitation remains unacknowledged.

#### *Lack of preparation for end of life and death of clients*

The review has highlighted the lack of attention paid to homecare workers’ experiences of a client’s death and there is little research on their preparedness in terms of their perceptions of client ‘suffering’ or distress, in contrast to the use of objective medical or client-reported experiences at the end of life (Riesenbeck et al. 2015). Furthermore, no assessments of work environments or care contexts in relation to staff preparedness for death have been undertaken (Riesenbeck et al. 2015). Homecare workers may act as a buffer to family

members' problems and so exploration into the nature of their interactions with family members is needed. Examples of this could include how support is provided, including information and advice, the medium used and timing (Roelands et al. 2005); the role mental health plays in terms of worker adaptation to client death (Boerner et al. 2015); and interpretation of grief to understand how these are perceived by individual homecare workers.

#### *Limitations of the studies reviewed*

Of the studies covered in this review, there are limitations worth noting. Firstly, there is a shortage of evidence in the UK context and with social care provision varying in different countries, the context of where and how formal care is provided is important to consider. Secondly, restrictions to single city locations and agencies in the studies reviewed limit the generalisability of findings. Additionally, the ethnicity and migration status of the care workers was not considered in most studies and should be factored into future studies. Ben-Arie and Lecovich (2014) and Boerner et al. (2015) acknowledged their neglect of worker ethnicity as a factor in shaping worker responses. Butler (2009) observed that her research was not conducted in an area where racial tensions and language barriers might arise, the impact of which may have had significant effect on the development of relationships between care worker and client. With homecare employers drawing on a large population of migrant workers (Browne & Braun, 2008), this needs to be addressed in understanding worker experiences and perceptions. Exploration of the differences between rural and urban areas as noted by Morgan et al. (2016) could be another way of addressing the impact of diversity.

#### *Implication for policy and practice*

Although home-based models of hospice and palliative care are being promoted, they are a relatively new initiative (Gomes, Calanzani, & Higginson, 2012; Department of Health, 2008) and the tasks undertaken by homecare workers will remain. Thus, homecare work may

become more specialised if it takes on more health-related tasks. Knowledge of the existing workforce's perceptions and experiences of providing care up to the end of life and, training and support needs will be helpful in workforce strategies and role redesign.

Recent government initiatives in England propose that health and social care staff should have the 'necessary knowledge, skills and attitude' to provide high quality end of life care (Department of Health, 2008, p.12) and that education and training related to end of life care should be directed to healthcare professionals (Department of Health, 2013). However, non-professional care staff, including homecare workers, may not have access to this education and training or find it valuable. In managing and supporting homecare workers, the National Institute for Health and Care Excellence (NICE) guidelines state homecare workers should be able to recognise and respond to support needs associated with bereavement, end of life and deterioration in someone's health (NICE, 2015). Yet the type of training and support needed by homecare workers remains undefined, under-funded, and under-researched.

## **Conclusion**

Our systematic review revealed a paucity of research exploring the reported experiences and feelings of homecare workers providing care up to end of life for people with dementia. The growth in this area of practice, along with rising demographic and social trends associated with ageing societies, indicates a possible need for more research on experiences, preparation and support needs from their perspectives. This research needs to focus specifically on those providing end of life care for people with dementia at home to inform skills development, training, service provision and relationships, and continuity of care work. The weakness in the evidence base presents challenges to homecare service managers, funders and providers looking for guidance on how best to design and deliver effective end of life care for people with dementia and how to meet the training and support needs of their employees.

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## References

Alzheimer's Society. (2011). *Support. Stay, Save: Care and support of people with dementia in their own homes*. London: Alzheimer's Society.

Alzheimer's Society & Marie Curie Cancer Care. (2014). *Living and dying with dementia in England: Barriers to care*. London: Alzheimer's Society and Marie Curie Cancer Care.

Retrieved from <http://www2.mariecurie.org.uk/Documents/policy/Dementia-report.pdf>

All-Party Parliamentary Group on Dementia (APPG) (2009). *Prepared to care: Challenging the dementia skills gap*. London: APPG. Retrieved from

[file:///C:/Users/Leon/Downloads/APPG\\_Report\\_Prepared\\_to\\_care.pdf](file:///C:/Users/Leon/Downloads/APPG_Report_Prepared_to_care.pdf)

Arts, S.E., Kerkstra, A., van Der Zee, J. & Huyer Abu-Saad, H. (1999). Workload, capacity for coping and psychological and physical outcomes amongst home helps in the Netherlands. *Health & Social Care in the Community*, 7(2), 79-90.

Ben-Arie, A. & Lecovich, E. (2014). Factors Explaining the Job Satisfaction of Home Care Workers Who Left Their Older Care Recipients in Israel. *Home Health Care Services Quarterly*, 33(4), 211-228.

Boerner, K., Burack, O. R., Jopp, D. S., & Mock, S. E. (2015). Grief after patient death: direct care staff in nursing homes and homecare. *Journal of Pain and Symptom Management*, 49(2), 214-222.

Bökberg, C., Ahlström, G., Leino-Kilpi, H., Soto-Martin, M. E., Cabrera, E., Verbeek, H., Karlsson, S. (2015). Care and service at home for persons with dementia in Europe. *Journal of Nursing Scholarship*, 47(5), 407-416.

Browne, C. V. & Braun, K. L. (2008). Globalization, women's migration, and the long-term-care workforce. *The Gerontologist*, 48(1), 16-24.

Butler, S. (2009). Women still taking care: The experiences of older home care workers. *Journal of Gerontological Social Work*, 52, 277-293.

Clarkson, P., Giebel, C. M., Larbey, M., Roe, B., Challis, D., Hughes, J. & Russell, L. (2016). A protocol for a systematic review of effective home support to people with dementia and their carers: components and impacts. *Journal of Advanced Nursing*, 72(1), 186-196.

Clinton, M., Conway, N. and Sturges, J. (2016). "It's tough hanging-up a call": The relationships between calling and work hours, psychological detachment, sleep quality and morning vigour. *Journal of Occupational Health Psychology*. Advance online publication.

Retrieved from

[https://pure.royalholloway.ac.uk/portal/files/26250310/Final JOHP Hanging up a calling Open Access.pdf](https://pure.royalholloway.ac.uk/portal/files/26250310/Final_JOHP_Hanging_up_a_calling_Open_Access.pdf)

Davies, E. and Higginson, I.J. (2004). *Better palliative care for older people*. Geneva, World Health Organisation.

Dawson, A., Bowes, A., Kelly, F., Velzke, K. and Ward, R. (2015). Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatrics*, 15(59), 1-17.

Devlin, M. and McIllfattrick, S. (2009). The role of the home-care worker in palliative and end-of-life care in the community setting: a literature review. *International Journal of Palliative Nursing*, 15(11), 526-532.

Devlin, M. and McIllfattrick, S. (2010). Providing palliative and end-of-life care in the community: the role of the home-care worker. *International Journal of Palliative Nursing*, 16(4), 195-203.

Department of Health. (2008). *End of Life Care Strategy-Promoting High Quality Care for All Adults at the End of Life*. London: DH. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136431/End\\_of\\_life\\_strategy.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf)

Department of Health (2013). *Improving Care for People at the End of their Life*. London: DH. Retrieved from <https://www.gov.uk/government/policies/improving-care-for-people-at-the-end-of-their-life>

Eaton, S. C. (2000). Beyond 'unloving care': Linking human resource management and patient care quality in nursing homes. *International Journal of Human Resource Management*, 11(3), 591-616.

Equality and Human Rights Commission (EHRC) (2011) *Close to Home: An Inquiry into Older People and human rights in homecare*. London: EHRC.

General Medical Council. (2010). *Treatment and care towards the end of life: good practice in decision making*. London, General Medical Council. Retrieved from [http://www.gmcuk.org/static/documents/content/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_life\\_-\\_English\\_1015.pdf](http://www.gmcuk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_1015.pdf)

Goodman, C., Froggatt, K. and Mathie, E. (2012). *End of Life – research methods review*, London, NIHR School for Social Care Research. Retrieved from <http://sscr.nihr.ac.uk/PDF/MR/MR12.pdf>

Gomes, B., Calanzani, N. and Higginson, I. J. (2012). Reversal of the British trends in place of death: time series analysis 2004–2010. *Palliative Medicine*, 26, 102-107.

Gott, M., Seymour, J.E., Bellamy, G., Clark, D. & Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine*, 18 (5), 460-467.

Gray, B. (2009). The emotional labour of nursing—Defining and managing emotions in nursing work. *Nurse Education Today*, 29(2), 168-175.

Health and Social Care Information Centre. (2014). *Community Care Statistics: Social Services Activity, England, 2013-14*. Leeds: Health and Social Care Information Centre.

Herber, O. R., & Johnston, B. M. (2013). The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review. *Health & Social Care in the Community*, 21(3), 225-235.

Hill, R.C., Dempster, M., Donnelly, M. and McCorry, N.K. (2016). Improving the wellbeing of staff who work in palliative care settings: A systematic review of psychosocial interventions. *Palliative Medicine*, Epub 2016 Mar 4.

Hussein, S. and Manthorpe, J. (2012). The dementia social care workforce in England: secondary analysis of a national workforce data set. *Aging and Mental Health*. 16(1), 110-118.

Igarashi, A., Kurinobu, T., Ko, A., Okamoto, Y., Matsuura, S., Feng, M. & Yamamoto-Mitani N. (2015). Factors related to the provision of home-based end-of-life care among home-care nursing, home help, and care management agencies in Japan. *BMC Research Notes*. 8: 434. doi: 10.1186/s13104-015-1418-z.

Kingsmill, D. (2014). *The Kingsmill Review: Taking Care. An independent report into working conditions in the care sector*. London: Baroness Denise Kingsmill.

Koehler, I. (2014) *Key to Care: Report of the Burstow Commission on the future of the home care workforce*. London: LGiU, the local democracy think tank and Mears. Retrieved from <http://www.lgiu.org.uk/wp-content/uploads/2014/12/KeyToCare.pdf>

Leadership Alliance for the Care of Dying People (2014) *One chance to get it right. Improving people's experiences of care in the last few days and hours of life*. Publications Gateway Reference 01509. London: Leadership Alliance for the Care of Dying People. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/323188/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf)

Mainemelis, C. (2001). When the muse takes it all: a model for the experience of timelessness in organizations. *Academy of Management Review*, 26(4): 548-565. doi:10.5465/AMR.2001.5393891.

Marie Curie (2009) *End of life care for people with dementia*. London: Marie Curie. Retrieved from <https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/past-initiatives/end-of-life-care-and-dementia/end-of-life-project-report.pdf>

McVicar, A. (2003). Workplace stress in nursing: a literature review. *Journal of Advanced Nursing*, 44(6), 633-642.

Morgan, D.G., Kosteniuk, J.G., O'Connell, M.E., Bello-Haas, V.D., Stewart, N.J. & Karunanayake, C. (2016). Dementia-related work activities of home care nurses and aides: Frequency, perceived competence, and continuing education priorities. *Educational Gerontology*, 42(2), 120-135.

Moriarty, J., Rutter, D., Ross, P. & Holmes, P. (2012). *End of life care for people with dementia living in care homes*. London: Social Care Institute for Excellence.

Murtagh, F.E.M., Bausewein, C., Petkova, H., Sleeman, K.E., Dodd, R.H., Gysels, M., Johnston, B., Murray, S., Banerjee, S., Shipman, C., Hansford, P., Wakefield, D., Gomes, B.



& Higginson, I.J. (2012). *Understanding place of death for patients with non-malignant conditions: A systematic literature review*. Southampton, Final report NIHR's Service Delivery and Organisation Programme research. Retrieved from [http://www.netscc.ac.uk/hsdr/files/project/SDO\\_FR\\_08-1813-257\\_V01.pdf](http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1813-257_V01.pdf)

NICE. (2015). *Home care: delivering personal care and practical support to older people living in their own homes*. London, NICE, Retrieved from <https://www.nice.org.uk/guidance/ng21/chapter/recommendations>

National End of Life Care Intelligence Network. (2013). *What we know now 2013: New Information collated by the National End of Life Care Intelligence Network*. London: Public Health England.

Piercy, K. W. (2000). When it is more than a job: Close relationships between home health aides and older clients. *Journal of Aging and Health*, 12(3), 362–387.

Raymond, M., Warner, A., Davies, N., Baishnab, E., Manthorpe, J., Iliffe, S., et al (2014). Evaluating educational initiatives to improve palliative care for people with dementia: A narrative review. *Dementia*, 13(3), 366-381.

Riesenbeck, I.V., Boerner, K., Barooah, A. and Burack, O.R. (2015). Coping With Client Death: How Prepared Are Home Health Aides and What Characterizes Preparedness? *Home Health Care Services Quarterly*, 34(3-4), 204-219.

Roelands, M., Van Oost, P., Depoorter, A. and Verloo, H. (2005). Knowing the diagnosis and counselling the relatives of a person with dementia: the perspective of home nurses and home care workers in Belgium. *Health and Social Care in the Community*, 13(2), 112-124.

Royal Pharmaceutical Society. (2014). *Handbook for home care services in England*. London: Royal Pharmaceutical Society. Retrieved from <http://www.rpharms.com/support-pdfs/homecare-services-handbook.pdf>

Rubery, J., Grimshaw, D., Hebson, G., & Ugarte, S. M. (2015). "It's All About Time": Time as Contested Terrain in the Management and Experience of Domiciliary Care Work in England. *Human Resource Management*, 54(5), 753-772.

Ryan, T., Nolan, M., Enderby, P. & Reid, D. (2004). 'Part of the family': sources of job satisfaction amongst a group of community-based dementia care workers. *Health and Social Care in the Community*, 12(2), 111-118.

Sampson, E.L., Gould, V., Lee, D. & Blanchard, M.R. (2006). Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing*, 35 (2), 187-189.

Stacey, C.L. (2005). Finding dignity in dirty work: the constraints and rewards of low-wage home care labour. *Sociology of Health & Illness*, 27 (6), 831-854.

UNISON. (2013). *Time to Care: A UNISON report into homecare*. London: UNISON.

Vandrevala, T., Samsi, K. and Manthorpe, J. (2015). Careful considerations in end-of-life care. *Nursing and Residential Care*, 17(6), 1-5.

Vandrevala, T., Samsi, K., Rose, C., Adenrele, C., Barnes, C. & Manthorpe, J. (2016). Perceived needs for support among care home staff providing end of life care for people with dementia: a qualitative study. *International Journal of Geriatric Psychiatry*. First published: 14 March 2016

Westerberg, K., & Tafvelin, S. (2014). The importance of leadership style and psychosocial work environment to staff-assessed quality of care: implications for home help services. *Health & Social Care in the Community*, 22(5), 461-468.

**Table 1. Search terms.**

Topic of interest	Search terms
Homecare worker	Home care aide, home health aide, personal care aide/assistant/attendant, direct care worker, domiciliary worker and support worker.
Dementia	Dementia, Alzheimer's
End of life	End of life, death, dying, palliative care

**Figure 1 PRISMA Flow Diagram of the review process**

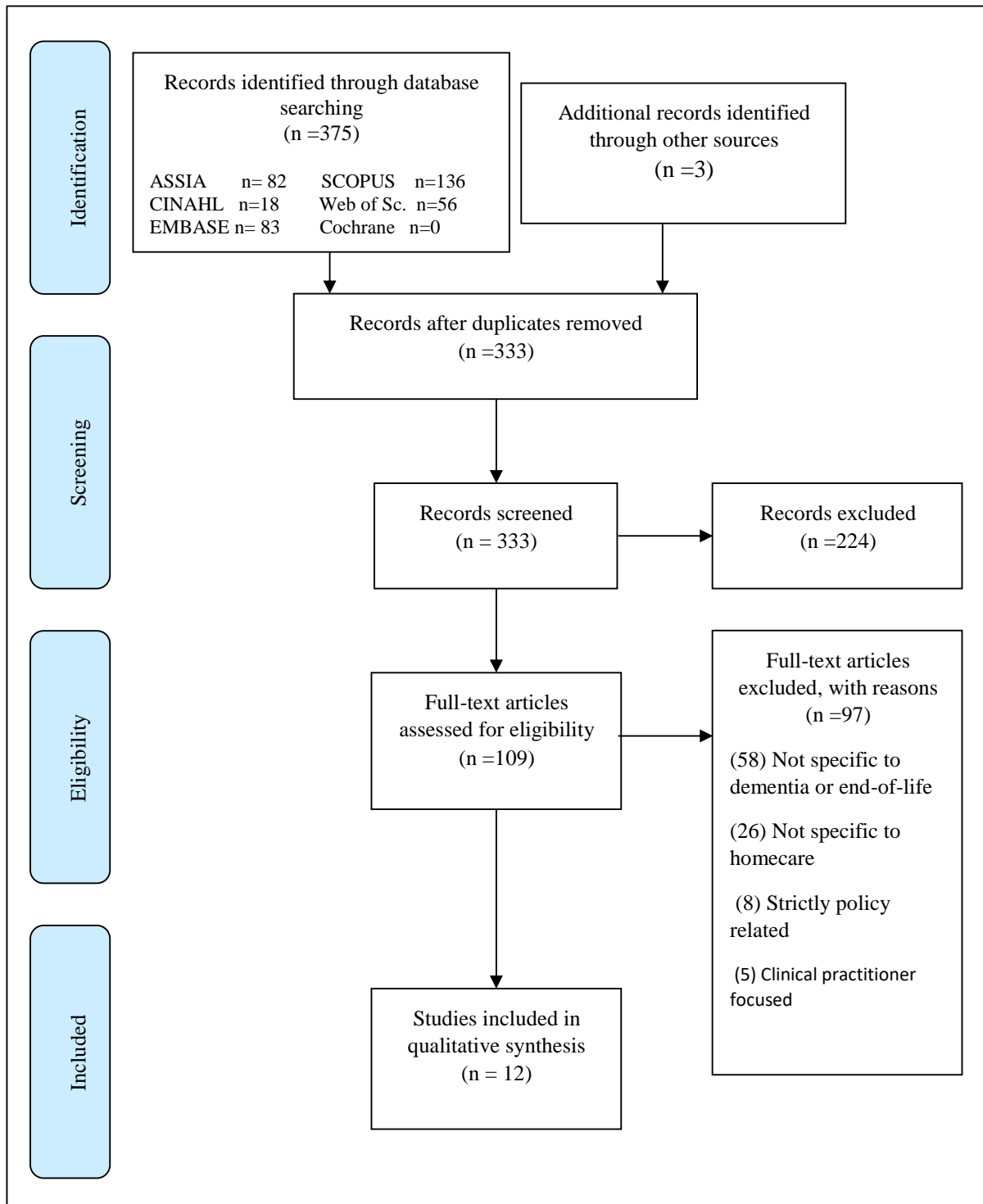


Table 2: Themes and sub-themes from data synthesis

A. Value of job role	<ol style="list-style-type: none"> <li>1. Role ambiguity and lack of role validation</li> <li>2. Feeling part of a team</li> <li>3. Remuneration</li> </ol>
B. Emotional labour	<ol style="list-style-type: none"> <li>1. Dementia-related work stress</li> <li>2. Emotional strain related to end of life care</li> <li>3. Limited emotional support</li> </ol>
C. Limited preparation	<ol style="list-style-type: none"> <li>1. Limited client information to prepare them for the role</li> <li>2. Need for dementia-specific end of life training</li> </ol>

**Table 3. Overview of papers included in the review (n=12) listed in alphabetical order.**

<b>Author/Year/Country</b>	<b>Focus of the study</b>	<b>Methodology and sample</b>	<b>Key Findings</b>
Ben-Arie & Lecovich (2014) Israel	Examined central factors associated with job satisfaction of homecare workers (HCWs) who had recently resigned from their jobs	197 HCWs Self-administered questionnaires 77% were women, average age of 45  Average 5.3 years of experience  Average length of provision of care was 1.8 months	Job dissatisfaction and greater work stress were associated with poorer functional (ADLs), cognitive status of care recipient and poor quality of relationship. HCWs providing care for people with cognitive impairment need ongoing support, training and supervision from their organisation.
Boerner et al. (2015) USA	Explored grief symptoms and preparation for death of care recipient by HCWs	140 Certified nursing assistants & 80 HCWs  In-person interviews using closed-ended questionnaires  Of the 80 HCWs, 96% female, average years in profession was 6.5 years, average months passed since client death, 1.8	Grief symptoms of care workers were similar to family carers'. Closer relationship, longer care provision and feeling unprepared for death contributed to HCWs' greater grief. HCWs need better training and support to prepare them for client death and may enable better palliative care.

Butler (2009) USA	Investigated experiences of older HCWs (55+) providing homecare to older people	7 women HCWs, aged 55+ Semi-structured interviews All participants were white and educated, average age was 63.6	HCW allows autonomy and job control, builds on relationships and caring, older women felt skilled and able to do the job. Pay is low and unreliable and HCWs are not valued. Improvement of HCWs image, training and reimbursement are needed to provide consistent service for older people who depend on their care.
Dawson et al. (2015) UK	Synthesised research evidence about effectiveness of services to support and sustain community-dwelling people with dementia and their carers	6 databases searched (CINAHL, IngentaConnect, Medline, ProQuest, PsychINFO and Web of Science) English language only, published since 2002. 26,980 records identified 131 publications evaluated	Limited research exploring needs or experiences of HCWs who support person with dementia (PWD) to live at home. Domiciliary support increasing role in end of life (EoL) care. An effective, supported workforce in partnership with informal carers is essential to care at home. No quality findings related to HCWs' training and support. Limited evidence base challenges ability to design and deliver support for people with dementia living in community.

Devlin & McIlfatrick (2009) UK	Literature review exploring role of HCWs in palliative and EoL care in community	4 databases searched (CINAHL, Medline, British Nursing Index and the Cochrane Library)  Search terms used individually and in combination included: 'palliative care', 'end of life care', 'community care', 'home help', 'homecare worker', 'social services' and 'formal carers'. Limited to English (2004-2009)	Confusion around role of HCW from health professional and patient/carer. Role of HCWs needs to be clarified, and they have unmet training needs in palliative care. Lack of research on role of HCWs in provision of EoL care.
Devlin & McIlfatrick (2010) UK	Explored role of HCWs in palliative and EoL care in community	69 HCWs completed questionnaire  6 community palliative care nurses  participated in a focus group	HCWs make significant contribution to meeting patient and family needs at EoL. Emotional impact of caring needs to be acknowledged, with support and supervision provided. Role of HCWs needs clarity and training
Herber & Johnston (2013) UK	Systematic review of literature on tasks/role and challenges of HCWs providing palliative and EoL care to people for people who want to die at home	Searched 7 databases using multiple search terms for HCWs, end-of-life, setting and patient group	Identified five core domains where HCWs contribute to end-of-life care: personal care; emotional and social support; domestic support; respite care for family carers and collaborating with professional and family carers.



Igarashi et al. (2015) Japan	Investigated the number and characteristics of EoL cases of a variety of homecare agencies	371 Home-care nursing, 274 Home-help and 452 Care management agencies completed a cross-sectional postal survey	Institutional preparedness for EoL was most important for home-help agencies.
Morgan et al. (2016) Canada	Examined frequency, perceived competence of specific dementia-related work activities and priorities for continuing education of dementia care among homecare nurses, case managers & nursing aides	Postal survey N=82 (41 aides, 20 nurses, 10 managers, 11 nurse/managers)  Compared 41 aides to 41 professional staff	Two activities central of nursing aides for PWD: personal care and helping with ADLs. Differences in priorities for continuing education between aides and professional staff highlight importance of assessing competence and education priorities of dementia care staff. Aides' areas of interest in continuing education may suggest expanding role and need for further education. Higher knowledge & competence may improve quality of care for people with dementia
Riesenbeck et al (2015) USA	Explored home health aides (HHAs) preparedness for client's death	Semi-structured interviews  80 HHAs (67% black/ 29% Hispanic)	Half of HHAs had not experienced client death previously.  Greater emotional preparedness was associated with HHAs who perceived their client was aware of dying and had some knowledge of client's EoL care preferences  Greater informational preparedness was associated with HHAs who perceived client as being in pain, knowing of dying, and had some knowledge of their care-related decisions and preferences  More information about client status, care preferences and care-related decisions may

			contribute to emotional and informational preparedness of HHAs for client death.
Roelands et al. (2005) Belgium	Explored conditions for, and practice of, effective counselling by homecare nurses and HCWs	Postal questionnaire 168 home nurses and 601 HCWs	Knowledge of a diagnosis of dementia necessary for effective counselling and care of PWD and providing emotional support to family. Knowledge of diagnostic and associated features of dementia was limited among HCWs.
Ryan et al. (2004) UK	Explored job satisfaction and influencing factors of HCWs through a new form of service provision for PWD	Interviews 7 HCWs at two points in time	Organisational features of home care to value and support HCWs through open channels of communication and availability of senior colleagues, as well as clear sense of purpose and part of team for HCWs contributed to job satisfaction. Additionally the ability of HCWs to forge and maintain good relationships with PWD & family and to believe they are making a difference influenced job satisfaction.