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"Earthly Angels"? A qualitative study of the domiciliary care worker role in meeting the needs of families caring for those dying at home

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ABSTRACT

Objective: Relatively little attention has been paid to optimum ways in which community-based care services can support family caregivers in the context of end-of-life care at home. This paper addresses such concerns by focusing on the services provided by domiciliary care workers.

Method: We draw on qualitative formal interviews with 42 family members, 1 patient, and 6 staff, as well as observation sessions and informal interviews with additional family caregivers and staff, to examine the aspects of domiciliary care perceived to be of most value. In particular, we compare and contrast family caregivers' experience of the support provided by generic domiciliary care workers with that of a team of specialist domiciliary care workers.

Results: Our findings show that specialist domiciliary care workers had sufficient time and expertise to meet family caregivers' physical and emotional needs in sensitive, proactive, and family-centered ways, and that these attributes were not so prominent in the services received from generic domiciliary care workers.

Significance of results: The availability to families of targeted support from an appropriately trained and carefully monitored team of specialist domiciliary care workers, able to operate flexibly and with staff consistency, appears to be an important foundation on which to build greater confidence in the reality of a good death at home.

KEYWORDS: Domiciliary care worker, End-of-life care, Family caregiver, Support needs

INTRODUCTION

An estimated half a million people provide informal care at the end of life, and family caregiving in this context is now an international research priority (Stajduhar et al., 2010). This may not be surprising, given that family caregivers are integral to the care of those at the end of life and crucial for enabling home death (Funk et al., 2010; Linderholm & Friedrichsen, 2010; Grande et al., 2009; Stajduhar et al., 2008; Kwak et al., 2007; Seymour et al., 2007).

Williams and McCorkle (2011) found in their systematic review that, in assuming the role of family carer for those with cancer, caregivers incur an increased risk of physical and mental morbidity and psychological stress. Indeed, family members may readily accept the end-of-life caring role, often because of the expectations of relatives and health professionals, but they may do so with ambivalence, fear, and anxiety, and without sufficient preparation or information (Linderholm & Friedrichsen, 2010). Furthermore, end-of-life family caregivers at home may assume that role for lengthy periods of time, sometimes over a year, which can lead to a sense of imprisonment (Andersson et al., 2010), and the responsibilities involved in end-of-life family caregiving tend to escalate and become more complex over time (Linderholm & Friedrichsen, 2010).

A number of studies detail the adverse effects of end-of-life caregiving, including anxiety, depression, and fatigue (Grande et al., 2009); financial, social,

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and relationship challenges (Stajduhar et al., 2010); worsening of physical health and difficulty revealing personal needs (Funk et al., 2010); and economic disadvantage (Aoun et al., 2005). For all these reasons, we need a better understanding of how best to support family caregivers so that they can deal with the range of challenges involved in helping to provide end-of–life care at home (Grande et al., 2009).

Applebaum and Breitbart (2012) systematically reviewed the psychological services that help reduce caregiver burden and found that structured, goal-oriented, and time-limited interventions that are integrative are of greatest benefit. Such interventions may help family caregivers maintain a normal relationship with their loved one, which Exley and Allen (2007) suggest can be seriously compromised by the responsibility of being a pivotal caregiver, and can also improve bereavement outcome (Grande and Ewing, 2009). As well as meeting psychological needs, home-based services should help provide respite care and attend to psychosocial, spiritual, and emotional needs (Stajduhar et al., 2010; Andersson et al., 2010). The Office for National Statistics National Bereavement Survey (ONS, 2012) found that, of the 11,269 family caregivers who responded to questions about support provided at home, 16% had received support but wanted more, 9% had not received support but had tried to get help, and 9% would have liked support but did not ask, the latter another indication of the lack of articulation of need referred to earlier. Healthcare providers sometimes lack resources and sufficient training to focus on the needs of both patients and family caregivers (Linderholm & Friedrichsen, 2010).

To summarize, the availability of community-located professionals who can both care for patients and support family caregivers appears to be a critical factor in the viability of home-based end-of-life care. The focus of our study, on which this paper is based, was the unique benefits of skilled workers and innovative services that make a positive difference in the lives of caregivers and their loved ones dying at home, often through seemingly inconsequential interventions, such as unhurried home visits and provision of respite care at short notice, which increase caregivers' confidence and resilience.

This paper explores the role of two types of domiciliary care workers. Domiciliary care workers (DCWs) usually have a generic workload but typically provide the majority of routine personal care and support required by end-of-life patients. Though not medically trained, they increasingly undertake tasks, such as percutaneous endoscopic gastrostomy (PEG) feeding, wound care, and stoma care, previously performed by registered nurses. In addition, they are commonly employed by private agencies (Watson, 2011). As part of a larger evaluation of end-of-life care provision in two counties in England (Marie Curie Cancer Center, 2012), we explored the role played by DCWs in meeting the emotional and practical support needs of family caregivers. Service provision in both counties included an end-of-life care coordination center, which received referrals from hospital- and community-based professionals and organized necessary care, including placement of DCWs.

In one county, referred to in this paper as District B, the end-of-life care coordination center could call on the services of domiciliary care workers in 18 different private agencies to provide care in their largely rural population. These agency staff were not specialists in end-of-life care. In the other county (District A), the end-of-life care coordination center had an in-house specialist team of eight domiciliary care workers who only cared for end-of-life patients and worked to NHS terms and conditions. This in-house team of specialist domiciliary care workers (SDCWs) was directly attached to the end-of-life care coordination center. The SDCWs themselves had a variety of professional backgrounds that included hospices and private care agencies, as well as previous experience as NHS healthcare assistants. However, this specialist team alone could not respond to the county-wide demand for personal care for end-of-life patients, and families often received additional or alternative care from domiciliary workers from the 10 private agencies operating in this mixed urban/rural county.

The aim of the present paper is to explore key themes affecting the quality of family support provided by SDCWs and agency domiciliary care workers (ADCWs), from the perspective of family caregivers themselves, to compare and contrast the experiences of each type of domiciliary care provision, and to examine important implications that arise.

METHODS

This work draws on the qualitative element of our evaluation. The methods employed included interviews and observations. We conducted in-depth face-to-face interviews with 42 family carers and 1 patient. To understand more about the DCW role and the different types of service provision, we interviewed six staff, including DCWs and other end-of-life care service providers. In order to obtain empirical data about the work that the SDCWs carried out, we undertook two observation sessions, during which informal interviews were carried out with two additional SDCWs, as well as relevant family members and patients. All interviews were recorded and transcribed, and, together with notes taken contemporaneously and following periods of observation, were subject to thematic and content analysis (Silverman, 2006). Analysis involved careful reading of each transcript, at least three times, which provided an opportunity for increased awareness of important and unifying subject domains, followed by progressive refinement of a robust scheme for coding themes and subthemes. As these themes and their components became clearer, so too did the proportional weighting attached to them by participants, which led to identification of comparisons and contrasts between components of the two types of DCW provisions. Observation notes were drawn on to refute or confirm themes arising from the interview analysis. An outline document with key findings was then drafted, and, in the interpretive phase, various members of the team met on several occasions to discuss this document, debate interpretations, and refine understandings before agreeing to the final set of themes.

RESULTS

In exploring the ways in which ADCWs and SDCWs met the emotional and support needs of family caregivers, we found that the following themes arose from our data:

- Sensitivity and consistency
- Proactive, family-centered approaches
- Allocation of sufficient time to meet physical and emotional needs of patients and family caregivers
- Close monitoring and flexible response to changing family needs
- Training and quality of care

Sensitivity and Consistency

The sensitivity and respect of DCWs appeared to help open a dialogue in which patient and family caregivers' fears and needs could be safely expressed and articulated, and practical advice given and understood. Informal interviews during research observations confirmed the importance of sensitivity and respect on the part of SDCWs.

From interviews with family caregivers we learned about the ability of SDCWs to provide care in a sensitive and respectful manner that impressed both patient and family caregivers, helping raise the credibility of SDCWs as caring individuals and professionals. Observations of domiciliary care workers during the course of research also confirmed the importance of sensitivity and respect. Relevant observation notes and caregiver responses are contained in Table 1.

Table 1. *Sensitivity and consistency*

Observation notes	After providing patient care, the two SDCWs sat down with the daughter, who talked about various things on her mind, including her mother's recent comment that she is "ready to die," and the daughter then asked some questions about managing her mother's oral care, which the SDCWs carefully explained. The SDCWs also advised the daughter not to worry about the need to constantly be doing things for her mother, that it is okay just to sit with her and have quality time. On leaving the house, the daughter kissed and embraced each of the SDCWs, which reinforced for me how quickly they can form a valued bond with family caregivers, given that in this case they have only been involved for three days. [Researcher's observation notes]
Caregiver responses	I couldn't have managed without them, without the confidence that I knew they were coming in (. . .) and the people themselves, they must have been trained, they were splendid (. . .) they were respectful, and gave [husband] all the kindness (. . .) and he had to be washed by them, and not once did he find it embarrassing or awkward. He accepted it all, because of their attitude; they were treating him gently, and knowing that he was a real true gentleman, with respect, right up until the end. [Mrs. MP] I think the continuity of the same people coming all the time is good (. . .) it's a much smaller team so everybody's got to know each other. [Mr. NG]. They [SDCWs] are more caring [than the ADCWs who also visit], I would say, because they know us well, because it's the same carers that come, they all know us, they've got used to us. [Mrs. RR, patient, and husband Mr. MR] We never had a continuing same person. It would have been better, having the same ones all the time (. . .) He [husband] was getting confident with one person and he would say "Well, why isn't so and so coming?" [Mrs. KV] If you have lots of different people out every day, which happened, you've kind of got to explain the story right from the word *go* every time. If you put yourself in the patient's position, where they are, perhaps, pretty helpless, and in bed, and you get a continual stream of strangers in, who you don't know, that's not wonderful. When you're dying, it's important to be surrounded by people you know and trust (Mrs. MV). One person who came to wash him, a gentleman actually, he was trying to tell us what to do in the end and I said, "Well I, you know, I'm old enough, I don't need to be told," and especially in my own home. So we had to ask the agency not to send him again. [Mrs. WJ]

Families who did not receive a service from the SDCW team also cited examples of sensitivity shown by the assigned ADCW staff, although this was mentioned much less often in interviews and also featured alongside accounts that workers did not take time to get to know an individual patient and family members or their tried and tested routines, as mentioned by Mrs. WJ in Table 1. Along with sensitivity, a subject that emerged throughout the interviews with family caregivers, was their appreciation of SDCW provision with respect to continuity of personnel, a highly valued aspect that helped confer confidence by establishing a personal bond, sometimes described as integral to a “caring” service and an aspect less apparent in anonymous and changeable ADCW teams, as suggested in the responses from Mr. NG and Mrs. RR and her husband MR in Table 1. Moreover, family members who only experienced ADCWs regretted that the private agencies on which they relied were unable to provide continuity of care, indicated by Mrs. KV and Mrs. MV in Table 1.

Proactive and Family-Centered Approaches

Family caregivers in this study cited situations where the SDCW team had flexibility and, most importantly, time to offer a solution to practical problems, reflecting a “can-do” approach that resulted in a family-centered, specially designed service. Responses from family members and one patient are included in Table 2.

This constructive, family-centered approach typically involved attention to the needs of family caregivers as well as patients, a point emphasized by Mrs. CJ, included in Table 2, who was especially grateful for the emotional and psychological support provided by SDCWs. Respondents often commented on how the SDCW team operated in a proactive manner, through engaging in discussion of additional practical ways to help. One example was how the team obtained a riser recliner chair following their observations of Mrs. RR’s increasing difficulty getting into and out of her living room chair, as Mrs. RR, a patient, explained during the interview and as referred to in Table 2. For Mrs. MP, also represented in Table 2, the SDCW team’s proactive approach helped raise her morale at a difficult time and reduce some of the physical demands of caring for her dying husband.

Allocation of Sufficient Time to Meet Physical and Emotional Needs of Patients and Family Caregivers

Sufficient allocation of time, enabling the SDCW team to engage flexibly, according to an individual family member’s changeable daily circumstances, was greatly appreciated, even if this sometimes resulted in lack of punctuality with regard to scheduled appointments, an inevitable consequence that respondents were often prepared to accept. Indeed, as the extracts in Table 3 suggest, the provision of sufficient time can be seen as a hallmark of a good-quality domiciliary care service.

There was some, though substantially less, evidence from families who received support from ADCWs that they also operate proactively, as Mrs. SC, a recently bereaved widow, indicated (see Table 3) when she told us that support workers who were “really worried” about her husband’s condition would contact district nurses, who would then visit. However, families also raised concern about ADCWs’ lack of time and their narrow task-oriented focus, as revealed by MV, in Table 3. Not all family caregivers criticized ADCWs’ lack of time and family focus, and presented positive examples of the support offered, such as Mr. CW, also quoted in Table 3. Notwithstanding the excellent care that some ADCWs

Table 2. *Proactive, family-centered approaches*

Caregiver responses	He died in the evening, but during that morning, I had this appointment and I said, I’ve got to go out, I’ll ask [son] to come down. And they [SDCWs] said, no, you won’t, we’ll organize that, and they organized it (. . .) so one of them stayed. [Mrs. YD] I think they are a lovely group, and they do a wonderful job both for the patient and for the relatives—I would like to stress that point. They will chat with you and help you to relax; if they think that they can, they probably like to do a little bit of counseling as well. Some are more trained to that than others, and I think, yes, I think it’s very good; on the whole, their attitude towards the relatives is very good. [Mrs. CJ] And I was asked, would you like more help in the evening, just to get him undressed, you see? And I could manage, actually, but it made it easier, made it easier for me (. . .) we used to call them our earthly angels, because they were, and I couldn’t have coped without them. [Mrs. MP]
Patient response	The carers kept on about getting a chair (. . .) kept on about it and kept on about it, and they all said “that’s all you need is a [riser recliner] chair; it’s going to take you up so that your feet come onto the floor,” and it does, it’s wonderful. It would take me ages to try and work myself forward to get up, and I was exhausted. [Mrs. RR]

Table 3. *Allocation of sufficient time to meet needs of patients and family caregivers*

Caregiver responses	They've [SDCWs] been a very good team; they can't always be on time, and they can't in fact give precise times because of course they won't leave a patient until, you know, they won't rush, which is good (. . .) they took over from a private contractor that was doing the job before, although they were reasonably [good] they had to be quick, they had to go and they seemed a little bit pressured, and they weren't able to give the sort of care that the [SDCWs] are providing you know. [Mr. NG] With agencies they come in specifically to wash, and that is their remit, and that is a totally different attitude from the end-of-life team [SDCWs] [who] are supportive; they are very supportive, and I think if one were very upset they would be able to help you a little. [Mrs. CJ] I felt with some of the people there [private care agency], that they were so rushed—this was a job, and they wanted to get it done as quickly as possible, and then on to the next job. [Mrs. MV] They [ADCWs] were on a very tight schedule, but the patient was more important; in many ways the care was better at home than in hospital. There was hardly a visit when [ADCWs] wouldn't say, "and are you [family caregiver] okay, are you managing?" Yes, so that was good; they were very aware. [Mr. CW]

provided, when family caregivers had had experience of both ADCW and SDCW provision, and were therefore able to make a comparison, they invariably favored the latter as more flexible, proactive, and family focused.

Close Monitoring and Flexible Response to Changing Family Needs

Embedded within the end-of-life care coordination service, SDCWs participated in daily briefings and regularly provided feedback to coordination center managers on their perceptions of changes in patient condition, or in family caregiver circumstances, information that could readily lead to refinements in level or timing of visits or lead to installation of other equipment:

> Since we've had the support workers [SDCWs] in place, they come in three times a week for handover and we get very up-to-date, very good information from them. It's more cohesive and we all know where we are. We all know what's happening to the patients, and it just sits a lot more comfortably. [Manager, District A end–of-life care coordination center]

Employing an in-house SDCW team also facilitated flexibility in resource allocation:

> By selecting and employing an in-house team [of SDCWs], the controls and monitoring are set by us [NHS managers] [and] we can react promptly. For example, I assessed a man in hospital in the morning. His wife desperately wanted him home as he was clearly dying, and by the end of the day he was home, as we were able to reschedule some visits that the [SDCWs] were doing to enable this. We were also able to provide a night-sit at very short notice by one of our team. We did not have to do the lengthy referral [for ADCW provision] with no guarantee that a sitter would be found. [Manager, District A end-of-life care coordination center]

This manager also commented that SDCWs conferred with each other to "rework" their daily schedules to accommodate any sudden increases in provision that were required. It is important to emphasize that the ability of the SDCW team to respond so flexibly to family needs was because this team was directly line managed by the end-of-life care coordination center staff, who had an up-to-date, comprehensive overview of end-of-life care provision across the county. Such a perspective was not available to ADCW managers, who would only be aware of the needs in their own small patch. Family caregivers who did not receive care from the SDCW team, and therefore relied on ADCWs, sometimes raised problems experienced when trying to get additional support, including night-sitters, and also spoke of the need for closer monitoring, so as to address variability in the quality of care.

Training and Quality of Care

SDCWs were expected to have achieved National Vocational Qualifications (NVQ) level 2 or 3 in health and social care, or show willingness to undertake such training within 18 months of employment. Specialist end-of-life care training was provided inhouse by three qualified and experienced community nurses who worked at the end-of-life care coordination center, where the SDCW team was based, and included mouth-care and simple wound dressing. Continuous ad hoc training was also provided in the course of daily briefings and supervision of the SDCWs, who, in addition, had access to a qualified nurse at all hours. SDCWs could also access online e-learning modules on end-of-life care cases.

In contrast, it is unclear to what extent ADCWs had regular supervision and training in end-of-life care. Healthcare professionals who were in a position to compare feedback they had received from family members who had received SDCW and/or ADCW input concluded that there were possible questions about the supervision and support of ADCWs by their managers. The end-of-life care coordination center that only supplied private agency staff had arranged end-of-life care training places for agency domiciliary care providers, to help improve end-of-life care knowledge in particular agencies, and had also signposted agencies to other educational sources of information, including relevant websites and Marie Curie Center training videos (e.g., on the use of syringe drivers). Despite such initiatives, healthcare professionals remained equivocal about the quality of staff and end-of-life care provided by the agencies, and caregivers also shared concerns about the quality and skill of ADCWs, as the content in Table 4 demonstrates.

Clearly, according to interviewees, lack of training of ADCWs can affect the potential to provide a holistic service, which in turn may adversely affect patient comfort at home.

DISCUSSION

The aim of our paper was to explore factors that affect the quality of family support provided by agency and specialist domiciliary care workers. We found that sensitive, consistent, proactive, family-centered, and flexible components of support were highly valued by family members, and that these features were more apparent in the service delivered by the SDCW team, due to the provision of sufficient expertise, continuity, and contact time.

The study had its limitations. Only one patient was formally interviewed, as most who were seen in the course of visits to family caregivers were too ill to participate. Nonetheless, the major focus of this paper was the experience of family caregivers, which was successfully captured. Second, as with qualitative descriptive studies, generalizability is an issue. For example, the skill mix and capabilities of staff in one ADCW team will not be the same as those in another, and caution is therefore required in reaching general conclusions about such provision. Furthermore, respective caseload sizes and lengths of time available for visits to patients are likely to differ between SDCWs and ADCWs, and are not easily comparable, given the exclusive end-of-life care remit of the SDCW team and its concerted family approach. Despite these issues, our findings give rise to important implications, based on distinctive service characteristics emphasized by research participants, in respect of ADCWs and SDCWs for these two counties. These characteristics are presented in Table 5.

In considering the implications of our data, along with evidence from studies reported earlier in this paper, particularly the pivotal role of family caregiving for people receiving end-of-life care at home, the challenges of anxiety, fatigue, and stress, and their needs for ready access to emotional and practical support, the following points are relevant:

Table 4. *Training and quality of care*

Healthcare professional response	We ought to make really sure that all the care providers we're using are all high quality; they can tell you that they've got all this [end-of-life care] experience, but who they send in is slightly different. [Manager, District B end-of-life care coordination]
Caregiver responses	The cancer was in the spine [and] it meant that he [husband] had no control of his functions (. . .) it was a private [agency], they're quite young; fairly unskilled girls came in to help, very pleasant, but I always was the other [hands-on] carer (. . .) I think some of them were trained in palliative care; some of the others certainly weren't; I had a word with their supervisor, not nastily. I just said I do think they need a wee bit more training. [author's italics] [Mrs. WL]
	The district nurse had brought out, they call it a slide sheet I think, but none of the [private care agency] people knew how to use it at all; they just weren't trained to do the job that they were being asked to do. I would have thought there would have been more what they call supervision for the [agency] girls because I think they were being asked to do things that really and truly they didn't have the knowledge to be able to do. [Mrs. IM]
	They [care agency workers] were supposed to come in, wash him [father], and get him up, and then put him to bed in the evening. But I didn't find that service particularly good [because] they were not allowed to do dressings; he had bed sores. So, I had to do all that (. . .) you would think they would be trained to deal with that, wouldn't you really? I think better-trained [support workers] would be the answer. When you are disturbing somebody who is not very well, it all needs to be done at the same time. I didn't think it was worth having them really. [Mrs. WB]

Table 5. *Respective DCW characteristics*

	Specialist Domiciliary Care Workers (SDCWs)	Agency Domiciliary Care Workers (ADCWs)
Characteristics of service	Small, eight-person team with NHS terms and conditions directly line managed by end-of-life care coordination center.	Dispersed personnel across 10 (County A) or 18 (County B) private agencies; not directly managed by end-of-life care coordination center.
	Continuity of personnel.	Variable or no continuity of personnel.
	Flexible and person-focused use of time.	Constrained and task-focused use of time.
	Highly relevant professional and personal experience in end-of-life care.	Varied, possibly little or no professional and personal experience in end-of-life care.
	Ongoing end-of-life care training.	Varied or no end-of-life care training.
	Regular thrice-weekly meetings with feedback to end-of-life care coordination center so that care could be adjusted.	Ad hoc contact with end-of-life care coordination center; dependency on families to report emerging care needs.
	Consistently proactive response to emerging needs.	Ad hoc response to emerging needs based on caliber and awareness of ADCW.
	Evidence of consistent sensitivity to patients and family caregivers.	Evidence of some sensitivity to patients and family caregivers depending on ADCW.

- The National End-of-Life Care Programme (NEoLCP, 2012, p. 5) emphasizes that care provision “needs to be flexible so that if the individual’s circumstances change the care package can change without any major delays.”
- A “proactive” and “preventative” approach may help prevent the adverse effects of informal care but is rarely attended to in research studies (Grande et al., 2009, pp. 339–342).
- The ability of support workers to step up their level of involvement and provide additional care to family members, as required, is evidence of innovative support that facilitates home deaths (NEoLCP, 2012).
- Knowledge of patient and family changes is dependent on flow of information, which support workers need to share “in a timely and appropriate manner” (Skills for Care, 2012, p. 14).

We found that the in-house structure of the SDCW team and its operational base within an end-of-life care coordination center enhanced the regularity with which feedback to managers was provided and improved information exchange within the small team, so that support could be flexibly and proactively adjusted. Such support attributes were not profiled in our interviews with family caregivers who had relied on ADCWs, and this may be because private agency DCWs tend to strictly adhere to allotted lengths of time (Baxter et al., 2008), which typically results in a short duration of calls (Patient and Client Council, 2012).

Family members who are caring for relatives at the end of life value sensitive, proactive, and experienced intervention, underpinned by well-trained professional support workers. According to the NHS National End-of-Life Care Programme, training is one of nine “critical success factors” that facilitate choice regarding preferred place of death and are crucial for general support workers delivering end-of-life care, given the fact that district nurse numbers are in decline and the pressures on those in post is growing (NEoLCP, 2012, p. 7). However, private agencies often work in “silos” and lack awareness and information about the “complexity” of end-of-life care provision (personal correspondence with Cheshire & Merseyside NHS Palliative and End-of-Life Care Network). It is therefore sobering to reflect that two fifths of the social care workforce hold no formal care-related qualifications, a situation exacerbated by the fact that the DCW turnover rate is around 20%, with over one in five leaving each year (CFWI, 2011). Indeed, according to a recent investigation by the BBC (British Broadcasting Corporation, 2012), more than 200 domiciliary care providers in England have been using staff without proper qualifications. It is not surprising to learn, therefore, that specialist, up-to-date training on end-of-life care is unlikely to be received by all agency care workers involved in its delivery (Skills for Care, 2010). More surprising, perhaps, is that there is “no formal requirement” for agencies that deliver end-of-life care to provide end-of-life care training or access specially designed qualifications (personal correspondence from “Skills for Care”).

Public policy in England has increasingly acknowledged that people’s ordinary home setting is their preferred place to receive end-of-life care (DH, 2008; 2012), a choice favored by almost three quarters of respondents involved in the first national survey of bereaved people in England (ONS, 2012). However, as we noted earlier on in this paper, studies emphasize a myriad of challenges faced by family caregivers, together with unmet support needs. Domiciliary care workers play a significant role in enabling home-based end-of-life care but too often lack sufficient resources, training, and time to provide good-quality continuity of care (Watson, 2011). Our findings are not nation- or culture-specific, and, indeed, many countries seeking to provide home-based end-of-life care services could profitably reflect on the benefits of specially appointed and well-resourced domiciliary care workers. In our opinion, the availability to families of targeted support from an appropriately trained and carefully monitored team of specialist domiciliary care workers, who are able to operate flexibly and with staff consistency, appears to be an important foundation on which to build greater confidence in the reality of "earthly angels" and to facilitate the possibility of a good death at home.

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REFERENCES

Andersson, M., Ekwall, A., Hallberg, I.R., et al. (2010). The experience of being next of kin to an older person in the last phase of life. *Palliative & Supportive Care*, *8*(1), 17–26.

Aoun, S.M., Kristjanson, L.J., Currow, D.C., et al. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine*, *19*(7), 551–555.

Applebaum, A.J. & Breitbart, W. (2012). Care for the cancer caregiver: A systematic review. *Palliative & Supportive Care*, *10*, 1–22.

Audit Scotland (2008). *Review of palliative care services in Scotland*. http://www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care.pdf.

Baxter, K., Glendenning, C., Clarke, S., et al. (2008). *Domiciliary care agency responses to increased user choice: Perceived threats, barriers and opportunities from a changing market. final report to the department of health*. http://www.york.ac.uk/inst/spru/research/pdf/provider.pdf.

British Broadcasting Corporation (BBC) (2012). *Unqualified home care worker figures revealed*. http://www.bbc.co.uk/news/health-19944217.

Centre for Workforce Intelligence (CFWI) (2011). *The adult social care workforce in England— key facts*. http://www.cfwi.org.uk/publications/the-adult-social-care-workforce-in-england-2013-key-facts.

Department of Health (DH) (2008). *End-of-life care strategy: Promoting high-quality care for all adults at the end-of-life*. London: HMSO.

Department of Health (DH) (2012). *End-of-life care strategy: Fourth annual report*. http://www.dh.gov.uk/health/files/2012/10/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf.

Dr Foster Intelligence (2012). *Hospital guide 2011*. http://drfosterintelligence.co.uk/wp-ontent/uploads/2011/11/Hospital_Guide_2011.pdf.

Exley, C. & Allen, D. (2007). A critical examination of home care: End-of-life care as an illustrative case. *Social Science & Medicine*, *65*, 2317–2327.

Funk, L., Stajduhar, K.I., Toye, C., et al. (2010). Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research (1998–2008). *Palliative Medicine*, *24*(6), 594–607.

Grande, G.E. & Ewing, G. (2009). Informal carer bereavement outcome: Relation to quality of end-of-life support and achievement of preferred place of death. *Palliative Medicine 23*(3), 248–256.

Grande, G., Stajduhar, K., Aoun, S., et al. (2009). Supporting lay carers in end-of-life care: Current gaps and future priorities. *Palliative Medicine*, *23*, 339–344.

Kwak, J., Salmon, J., Acquaviva, K.D., et al. (2007). Benefits of training family caregivers on experiences of closure during end-of-life care. *Journal of Pain and Symptom Management*, *33*(4), 434–445.

Linderholm, M. & Friedrichsen, M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, *33*(1), 28–36.

Marie Curie Cancer Center (2012). *Independent evaluation of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset*. http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/commissioning-services/Delivering-Choice-Proramme-in-Somerset-and-North-Somerset-Final-Report.pdf.

National Council for Palliative Care (NCPC) (2011). *NCPC Specialist Palliative Care Workforce Survey and Specialist Palliative Care Longitudinal Survey of English cancer networks, 2010*. http://ncpc.org.uk/publication/specialist-palliative-care-workforce-survey.

National End-of-Life Care Programme (NEoLCP) (2012). *Developing end-of-life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end-of-life care*. http://www.endoflifecareforadults.nhs.uk/publications/corecompetencesframework.

Office for National Statistics (ONS) (2012). *National Bereavement Survey (VOICES), 2011*. http://www.ons.gov.uk/ons/dcp171778_269914.pdf.

Patient and Client Council (2012). *Care at home: Older people's experiences of domiciliary care*. http://www.patientclientcouncil.hscni.net/uploads/research/Care_at_Home.pdf.

Royal College of Nursing (RCN) (2012). *District nursing concerns*. http://www.rcn.org.uk/newsevents/news/article/eastern_stories/concern_about_cuts_in_district_nursing.

Seymour, J., Payne, S., Chapman, A., et al. (2007). Hospice or home? Expectations of end-of-life care among white and Chinese older people in the UK. *Sociology of Health & Illness*, *29*(6), 872–890.

Silverman, D. (2006). *Interpreting qualitative data: Methods for analysing talk, text and interaction*, 3rd ed. London: Sage.

Skills for Care (2010). *The state of the adult social care workforce in England, 2010*. http://www.skillsforcare.org.uk/

research/research_reports/state_of_the_adult_social_care_workforce_reports.aspx.

Skills for Care (2012). *Common core principles and competences for end-of-life care*. http://www.skillsforcare.org.uk/publications/publications_c.aspx.

Stajduhar, K.I., Martin, W.L., Barwich, D., et al. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing*, *31*(1), 77–85.

Stajduhar, K.I., Funk, L., Toye, C., et al. (2010). Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998–2008). *Palliative Medicine 24*(6), 573–593.

Watson, H. (2011). Challenges of domiciliary carers when providing end-of-life care. *End of Life Journal* (online). http://endoflifejournal.stchristophers.org.uk/professional-issues/challenges-of-domiciliary-carers-when-providing-end-of-life-care.

Williams, A.-L. & McCorkle, R. (2011). Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature. *Palliative & Supportive Care*, *9*(3), 315–325.