

Understanding the Role and Contribution of Health Care Assistants in Out-of-Hours Community Palliative Care: A Multiple Qualitative Case Study

Yasmin Farouk^{1*}, Hana Mostafa¹, Salma Adel²

¹*Department of Integrative Nursing Care, Faculty of Nursing, Mansoura University, Mansoura, Egypt.*

²*Department of Palliative Medicine, Faculty of Medicine, Alexandria University, Alexandria, Egypt.*

Abstract

Around the world, the designations, functions, and training of unregulated healthcare staff remain unstandardized. Nevertheless, a growing body of evidence indicates that these workers are vital to the delivery of palliative services. In the United Kingdom, a Health Care Assistant (HCA) is an unregulated member of the workforce who delivers patient support under the direct oversight of registered practitioners across diverse medical environments. Although the availability of community-based, out-of-hours (OOH) palliative care is recognized globally as a critical priority, there remains a significant knowledge gap regarding the specific duties and impacts of HCAs in providing this type of care. To explore the specific roles, duties, and overall contributions of HCAs in community-based, out-of-hours palliative care settings. This study employed a qualitative case study design to examine six distinct out-of-hours palliative care service structures operating across the UK. Data collection involved gathering multi-perspective accounts through interviews with managers, family carers, specialist nurses, and HCAs. Between 2021 and 2022, 59 semi-structured interviews were conducted. The collected interview data were subsequently examined using framework analysis. The analysis yielded two primary themes: the systemic and operational complexities of the service and role, and the specific impact of the HCA within the OOH community palliative care. Both themes highlight the highly inconsistent environments characterizing OOH community palliative care, where Health Care Assistants carry out their duties. The findings revealed that HCAs offer hands-on care for dying individuals alongside psychological and social support for their families. Furthermore, they frequently served as the primary staff members responsible for detecting clinical changes in patients, fulfilling a vital role in identifying, managing, and escalating clinical needs. Respondents noted that these actions played a meaningful part in helping patients remain in their own homes. Gaining a clearer understanding of both the structural delivery of out-of-hours palliative care and the specific duties of Health Care Assistants is essential to building organizational frameworks that optimize patient support. Because existing evidence remains sparse, additional research is required to determine how adjusting these organizational elements can improve care delivery and maximize the overall utility of the Health Care Assistant within palliative services.

Keywords: Out-of-hours, Hospice, Community, Health care assistants, Organizational case study, End-of-life

Introduction

Faced with rapidly aging populations, healthcare systems worldwide are currently experiencing widespread workforce shortages, prompting increased reliance on unregulated healthcare personnel [1-3]. On an international level, this role has shifted from a purely supportive capacity to one that incorporates complex nursing duties historically handled by registered staff [4-6]. Even so, there is no global consensus regarding the professional

Corresponding author: Yasmin Farouk
Address: Department of Integrative Nursing Care, Faculty of Nursing, Mansoura University, Mansoura, Egypt.
E-mail: ✉ yasmin.farouk@gmail.com
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titles, clinical boundaries, or required training for this position, nor is there a uniform approach to licensing or regulation [4, 7]. The titles assigned to the healthcare assistant role differ by country, spanning from nurse care workers in China [8] to personal care assistants and nursing assistants in Australia [9]. Across Europe, numerous titles are utilized, though the designation Health Care Assistant (HCA) remains the most widely adopted [1].

In the United Kingdom (UK), the unregulated workforce is generally designated by the HCA title. There is no statutory regulation for this group, even under the Care Quality Commission, which serves as the independent regulator monitoring the safety and quality of care services. Although literature indicates that these workers sometimes experience a lack of professional recognition within their teams [10, 11], HCAs remain fundamental across numerous healthcare settings, including home-based community palliative care [12-14]. In the UK context, community palliative care refers to services provided outside outpatient clinics and hospital wards, most notably in patients' private residences [15].

Most existing research on the HCA role in palliative care has focused on community settings, indicating that these staff members provide the majority of hands-on patient care [16] and are often the first to identify and report changes in a patient's status to specialist practitioners [17, 18]. Evidence demonstrates that they can generate highly precise evaluations of subtle changes in a patient's clinical state, enabling them to foresee the transition toward the terminal phase [19] up to, and including, the time of death [20, 21]. Because they frequently form relationships akin to a 'friendship' with patients and family members [17], they are recognized as essential in facilitating end-of-life dialogues and providing psychosocial care [22, 23]. This close contact simultaneously increases their vulnerability to the psychological weight of witnessing patient deterioration, physical suffering, and family grief. Facing these circumstances repeatedly exposes HCAs to risks of secondary traumatic stress and vicarious trauma, particularly within palliative and end-of-life care contexts where death, bereavement, and anticipatory mourning are everyday occurrences [24-26].

However, even though data indicate that HCAs represent a crucial segment of the OOH community palliative care workforce [27], their exact responsibilities and contributions remain under-researched [28]. The structure of out-of-hours care varies internationally; within the UK, it covers the period from 18.30 to 08.00 on weekdays, with full coverage on weekends and public holidays. This OOH period accounts for 63% of the weekly calendar, during which standard daytime primary care resources are closed [29, 30]. Because a large proportion of palliative care patients express a preference to receive care and pass away within their own homes [31, 32], OOH services have been designated as an essential focus for policy and research within both the UK and Ireland [33, 34].

While similarities can be drawn between the duties of HCAs in home care during the OOH timeframe and those working in inpatient facilities, critical operational differences exist. Navigating OOH community palliative care presents distinct challenges, including volatile home environments, regional service disparities, communication and coordination barriers among agencies, inconsistent training on end-of-life protocols, and the need to balance conflicting preferences among families and patients [30, 35]. During out-of-hours periods, individuals receiving palliative care have been found to experience an elevated risk of clinical harm, particularly concerning the evaluation and control of physical symptoms [36]. Lastly, whereas inpatient HCAs receive immediate oversight while working alongside multi-professional teams—ensuring rapid access to specialist guidance—OOH community HCAs generally function as lone, independent field workers. For these staff members, clinical supervision is handled remotely, forcing them to independently navigate highly fluid and unpredictable care settings [7, 37].

Primary difficulties in providing OOH community palliative care include evaluating complex symptom presentations, making prognostic determinations, and promptly escalating clinical concerns [30, 38]. In the UK out-of-hours framework, registered professionals such as District Nurses (DNs) or specialist clinicians are typically required to administer medications. However, this administration can face extensive delays stemming from travel distances or the absence of pre-prescribed anticipatory medications at home, even when dedicated OOH 'rapid response' nursing teams are available [39]. Prolonged waiting intervals can lead to symptoms going unmanaged in domestic environments [40]; consequently, field staff, including HCAs, are placed in highly stressful positions where they must manage these crises while enduring substantial emotional and psychological strain [41-43].

Gaining insight into how HCAs function as team members is crucial for fostering multidisciplinary integration and optimizing care delivery [1]. This investigation aims to evaluate the responsibilities and duties of HCAs, thereby offering a more definitive perspective on their contributions to out-of-hours community palliative care.

Materials and Methods

Study design and setting

To evaluate how HCAs function and add value within out-of-hours (OOH) community hospice programs, this study utilized six organizational case studies [44] across adult hospices in the UK. In this research, 'the case' was defined as the operational integration of HCAs within each respective hospice service. Participants were drawn from an earlier national survey [27] targeting adult hospices that offer OOH community palliative care; from this

cohort, four service providers meeting the specified selection criteria volunteered to participate (**Table 1**) [45]. The configurations of these OOH services spanned four distinct styles: multi-visiting ($n = 1$), Planned Variable ($n = 1$), Rapid Response ($n = 1$), and Hospice at Home ($n = 3$). Although the teams differed in their overall size, composition, and specific OOH delivery model, all included HCAs as part of their frontline workforce. By utilizing a multiple organizational case study approach, the researchers were able to draw comparisons across distinct settings, thereby helping to “generate in-depth, multi-faceted understanding of a complex issue in its real-life context” [46]. In keeping with established research practices in the palliative field [47, 48], the analytical framework embedded data from multiple internal and external stakeholders, including managers, specialist nurses, family carers, and the HCAs themselves. Methodological transparency and research rigor were maintained by strictly following the COREQ reporting guidelines [49].

Table 1. Inclusion criteria for organizational cases. From: Health care assistants in out-of-hours community palliative care: multiple qualitative organizational case studies.

Eligibility criteria	Description
Type of hospice	Adult hospices operating within the United Kingdom.
Registration status	Included in the Hospice Aid UK database.
Out-of-hours (OOH) community palliative care services are provided	Hospices were required to offer one or more forms of OOH community palliative care services, including the following:
Planned variable care	Pre-arranged nursing support is delivered in shifts lasting eight or nine hours, most commonly during overnight periods.
Rapid response service	Emergency palliative care assistance is provided in the patient’s home, available through a 24/7 specialist on-call service.
Hospice-at-home service	Delivery of palliative care interventions within the home setting, enabling patients to receive care in their usual residence.
Multi-visiting service	Provision of shorter care encounters, typically involving several visits by nursing staff during a single work shift.

OOH Service involves HCA as a staff member

Participants and recruitment

Informants were selected via purposive sampling strategies (**Table 2**). Initial recruitment was facilitated by community hospice administrators at each site, who managed or interacted directly with the OOH community palliative services. Before starting data collection, the researchers had no personal or professional acquaintance with any of the participants.

Table 2. Inclusion criteria. From: Health care assistants in out-of-hours community palliative care: multiple qualitative organizational case studies.

Eligibility criterion	Hospice staff	Current caregiver	Bereaved caregiver
Role/Status	Employed in the out-of-hours service model as a healthcare assistant, nurse, healthcare practitioner, or manager.	Identified as the main caregiver of an individual receiving palliative care at home.	Identified as the principal caregiver of a person who previously received home-based palliative care and is now deceased.
Study participation	Agreed to take part in the research and provided informed consent.	Agreed to participate in the research and provided informed consent.	The individual they cared for had died more than three months ago.
Age requirement	18 years or older	18 years or older	18 years or older
Capacity to participate	—	Considered physically and emotionally capable of participating in the study.	Considered physically and emotionally capable of participating in the study.
Language and consent requirements	—	Able to provide written consent and communicate in spoken and written English or Welsh.	Able to provide written consent and communicate in spoken and written English or Welsh.

Though the research team originally intended to gather data from patients, this was not possible due to the broader impacts of the COVID-19 pandemic—specifically, an influx of late-stage referrals, which left individuals frequently too debilitated to participate by the time they engaged with the OOH service.

Data collection

The fieldwork for this project relied on documentary analysis alongside semi-structured, one-to-one online interviews. A total of 59 online interviews were completed, comprising contributions from administrators/managers ($n = 8$), HCAs ($n = 24$), registered nurses ($n = 16$), active carers ($n = 6$), and bereaved carers ($n = 5$). All interviewees received descriptive study materials and supplied written informed consent before

participation. The semi-structured interview schedule was designed around the core study objectives and informed by findings compiled during earlier stages of the broader project [27, 28, 50]. These interview frameworks were implemented flexibly, allowing the researchers to explore the participants' professional backgrounds and capture detailed accounts of their experiences with OOH community palliative operations. The sessions were digitally recorded with participants' written consent, lasted 18-67 min, and were conducted by a team of three female investigators. This team included two dedicated researchers (AF, CS) and one senior academic (FH), all of whom were experienced in qualitative inquiry and recorded reflective field observations following every session.

Although the interviewing team did not have formal clinical training, their prior experience interviewing hospice staff and families enabled them to navigate these interactions with appropriate sensitivity, and reflexive practices were maintained throughout to minimize potential investigator bias. Data collection occurred between July 2021 and April 2022, and all audio recordings were transcribed word-for-word. The research team monitored for data saturation during fieldwork, determining that it had been achieved when subsequent interviews merely reinforced established concepts without yielding any novel themes. Each case study site received an incentive of £1000 for participating, and all of the involved hospices elected to distribute a portion of these funds to their staff as gift vouchers.

Data analysis

To permit rigorous comparisons both within individual sites and across the different organizational settings, the transcripts were analyzed using a framework approach [51]. The typed texts were first audited against the original audio files to verify accuracy, followed by an iterative process of reading and re-reading to achieve deep data familiarization. Next, line-by-line coding was executed to construct an initial coding framework, and the data files were imported into NVivo 12 qualitative analysis software [52] for systematic organization. This process led to the creation of a preliminary thematic index to capture factors related to HCAs' roles and contributions during out-of-hours community palliative shifts. The raw transcripts were then fully indexed using this system. Through this methodology, codes and themes specific to the HCA's duties and impact were isolated and evaluated across different settings to identify influential contextual variables.

The analysis was a collaborative effort; the research team (FH, AF, & CS) collectively refined and finalized the coding index, resolving any interpretive differences through academic dialogue until a consensus was achieved. The indexed data segments were then plotted into framework matrices to facilitate systematic cross-referencing. Conducting within-case analysis provided a comprehensive view of each separate location. In contrast, cross-case analysis enabled the team to identify broader, cross-cutting themes and assess how different environments affected the HCA role [48]. Through an ongoing process of conceptual mapping and interpretation, two core themes were ultimately established and refined. Paraphrased accounts and specific text segments are utilized throughout the narrative to illustrate typical participant perspectives.

Rigour

Methodological quality was maintained by adhering to established standards for qualitative trustworthiness [53]. To optimize confirmability, the interview transcripts were subjected to iterative readings and independent reviews by three separate members of the research team. This process enhanced interpretive transparency and limited individual researcher bias. Credibility was reinforced by recruiting individuals with direct, firsthand experience with the specific phenomena under review and by maintaining a consistent interview schedule. Dependability was supported by maintaining a detailed audit trail that tracked all analytical turning points. At the same time, transferability was facilitated by providing comprehensive descriptions of the study settings and participant demographics.

Results and Discussion

The final analysis incorporated six organizational cases representing the experiences of 59 contributors (**Table 3**). The findings are structured as a cross-case analysis. They are divided into two main categories: (a) service and role complexity, and (b) the overall impact of the HCA within the OOH community palliative care.

Table 3. Participant characteristics. From: Health care assistants in out-of-hours community palliative care: multiple qualitative organizational case studies.

Case characteristics	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6 (Arthur rank/Hospice of the valleys)
Geographical location	Northern Ireland	Northern Ireland	Northern Ireland	Northern Ireland	England	Wales
Out-of-hours (OOH) service model	Multi-visiting service (8 am–11 pm)	Planned variable service (night-sitting model)	Rapid-response service	Hospice-at-home service	Hospice-at-home service	Hospice-at-home service

Additional services available	Inpatient palliative care unit (n = 14–18 beds), community palliative care team, home nursing, and day-care services	Inpatient palliative care unit (n = 14–18 beds), community palliative care team, home nursing, and day-care services	Inpatient palliative care unit (n = 14–18 beds), community palliative care team, home nursing, and day-care services	Inpatient palliative care unit (n = 17 beds), hospice hub, and community-based services	Inpatient palliative care unit (n = 23 beds), hospice hub telephone support line for palliative care	Community-based nurse specialist services with access to a medical consultant
Total participants (n)	17	8	8	10	10	6
Participant roles	Healthcare Assistants (n = 7); Administrators/Managers (n = 0); Nurses (n = 2); Active carers (n = 5); Bereaved carers (n = 3)	Healthcare Assistants (n = 2); Administrators/Managers (n = 0); Nurses (n = 5); Active carers (n = 1); Bereaved carers (n = 0)	Healthcare Assistants (n = 2); Administrators/Managers (n = 2); Nurses (n = 4); Active carers (n = 0); Bereaved carers (n = 0)	Healthcare Assistants (n = 5); Administrators/Managers (n = 1); Nurses (n = 2); Active carers (n = 0); Bereaved carers (n = 2)	Healthcare Assistants (n = 4); Administrators/Managers (n = 4); Nurses (n = 2); Active carers (n = 0); Bereaved carers (n = 0)	Healthcare Assistants (n = 4); Administrators/Managers (n = 1); Nurses (n = 1); Active carers (n = 0); Bereaved carers (n = 0)
Relationship of carers to the patient	Wife (n = 3); Child (n = 2); Daughter-/son-in-law (n = 1)	Child (n = 2); Daughter-/son-in-law (n = 1)	—	Child (n = 1)	—	—
Gender distribution	Male (n = 0); Female (n = 18)	Male (n = 1); Female (n = 4)	Male (n = 0); Female (n = 8)	Male (n = 0); Female (n = 9)	Male (n = 0); Female (n = 4)	Male (n = 1); Female (n = 5)
Age profile	31–50 years (n = 7); 51–65 years (n = 9); 66+ years (n = 2)	31–50 years (n = 2); 51–65 years (n = 3)	31–50 years (n = 4); 51–65 years (n = 4)	31–50 years (n = 4); 51–65 years (n = 5)	18–30 years (n = 1); 31–50 years (n = 2); 51–65 years (n = 1)	18–30 years (n = 1); 51–65 years (n = 4); 66+ years (n = 1)
Ethnic background	White (n = 18)	White (n = 5)	White (n = 8)	White (n = 9)	White (n = 4)	White (n = 6)
Educational attainment	NVQ/GCE/GCSE (n = 1); A-level (n = 7); Degree (n = 4); Other qualifications (n = 1)	Degree (n = 2)	NVQ/GCE/GCSE (n = 2); A-level (n = 0); Degree (n = 5); Higher qualification (n = 1); Other (n = 2)	NVQ/GCE (n = 1); GCSE (n = 0); A-level (n = 3); Degree (n = 4); Higher qualification (n = 0); Other (n = 3)	NVQ/GCE (n = 1); GCSE (n = 0); A-level (n = 0); Degree (n = 3); Higher qualification (n = 0); Other (n = 1)	NVQ/GCE (n = 2); GCSE (n = 0); A-level (n = 2); Degree (n = 1); Higher qualification (n = 0); Other (n = 1)

Demographic tables are provided for the six included case sites, summarizing the characteristics of the 59 contributors.

Theme: service and role complexity

Across all sites, the overriding goal of OOH hospice community palliative services was to assist patients and manage their physical symptoms effectively, enabling them to spend their final days at home. Participants widely recognized that the successful execution of this care depended heavily on smooth integration with alternative entities across acute, community, and social service sectors. Even so, respondents drew sharp contrasts between daytime operations and out-of-hours care, identifying unique systemic challenges such as reduced service accessibility, medication shortages, and limited workforce availability during the OOH window.

Regarding these challenges, one HCA (S1P1) noted that while an out-of-hours telephone support line and an on-call manager were technically available, the remote nature of the service meant they frequently reached coordinators based in entirely different regions, such as Wales. This professional explained that these distant managers often lacked local geographic awareness, leaving field staff feeling isolated when navigating difficult, remote terrain.

Furthermore, a registered nurse (S3P8) described the profound professional distress caused by supply issues, noting that teams frequently faced situations in which they lacked access to the medications necessary to comfort patients, a scenario they characterized as deeply troubling.

The structural deficit in out-of-hours medical coverage was also raised by a manager (S3P1), who pointed out that the complete absence of physical, on-the-ground out-of-hours GPs left a severe workforce vacuum. They explained that while triage nurses remained at the central base, the lack of mobile medical personnel placed an overwhelming operational burden entirely on their own field staff and visiting Marie Curie nurses.

Compounding these structural gaps, another manager (S4P1) detailed the significant logistical difficulties of managing remote referrals with a depleted workforce. This administrator explained that they frequently had to ask HCAs to undertake extensive round trips of up to 50 miles, coordinating these assignments via email using

whatever sparse information was available, such as basic driving directions or instructions on how to access the property via a secure key safe code.

While every member of the out-of-hours team was essential to maintaining operations, clear differences emerged regarding the responsibilities and overall availability of specialist nurses compared to HCA staff during the OOH shift. Most specialist nurses, particularly those involved in rapid response duties or supporting hospice-at-home models, reported experiencing immense professional strain. They attributed this pressure to a combination of rising palliative care referrals and heightened clinical complexity, all occurring alongside widespread staffing shortages. These structural stressors, coupled with unpredictable travel times and varying visit durations, placed significant demands on their professional capabilities. As respondents observed:

A manager (S1P12) emphasized that out-of-hours personnel represent an incredibly scarce and valuable organizational asset. They observed that the available workforce drops significantly during these hours, precisely when the patient population is experiencing increasingly complex clinical needs and rising service demands.

This sentiment was echoed by a specialist nurse (S4P4), who explained that the size of their staff entirely constrains the viability of the hospice-at-home out-of-hours service. Because they operate with such a small team, they observed that palliative patients frequently encounter severe barriers when seeking assistance out of hours. Both registered nurses and administrative managers recognized HCAs as vital components in the operational framework of out-of-hours (OOH) hospice community palliative services. In contrast to registered clinicians, who possess advanced academic credentials in the palliative field, HCAs maintained the longest, most direct contact with patients and their relatives. This sustained presence enabled HCAs to develop a nuanced understanding of individual care needs, domestic routines, and behavioral patterns, which they actively applied to tailor clinical support. This close involvement additionally helped HCAs cultivate a strong rapport and a sense of psychological safety with families. Both current and former family caregivers emphasized that extended access to a single staff member was essential for tailoring patient care, securing much-needed caregiver respite, and establishing a safe environment to express anxieties, apprehensions, and personal preferences. Many caregivers recalled that once the patient was comfortable, they utilized this time with the HCA to process their own feelings regarding mortality, the dying trajectory, and subsequent grief.

In academic terms, active caregivers observed that the informal, friendly nature of these interactions made them feel comfortable opening up to HCAs. They noted that these workers consistently monitored the caregiver's well-being and actively encouraged them to rest and practice self-care, offering practical assistance whenever possible (S3P10, Active Carer).

Other caregivers highlighted the broader advocacy and systemic support provided by HCAs during emotionally overwhelming periods. One informant recalled that an HCA provided valuable guidance on the social services they were entitled to request, such as a formal carer's assessment, and even intervened directly by contacting a social worker on multiple occasions to coordinate support (S4P9, Active Carer).

When detailing their core clinical boundaries, HCAs initially identified technical and practical tasks, including patient mobilization, personal hygiene maintenance, infection control protocols, the monitoring of specialized equipment such as syringe drivers, and post-mortem care, which involved washing, positioning, and dressing the deceased while managing any remaining medical devices and respecting the cultural and spiritual wishes of the family. Beyond these physical interventions, they noted their critical involvement in family education, resource signposting, emotional counseling, and the mediation of interpersonal conflicts or acute grief reactions within the wider family unit. The data further indicated that HCAs routinely engaged in complex dialogues with patients and relatives regarding the progression of the underlying disease, symptom tracking, the clinical transition into the active dying phase, immediate end-of-life care, and the bereavement process.

From the perspective of frontline staff, HCAs reported that patients often utilized these visits to discuss the reality of their medical conditions because they wished to shield their own relatives from emotional distress. Consequently, the arrival of the HCA provided patients with an outlet to speak candidly about their changing clinical presentation and what to anticipate moving forward (SP12, HCA).

Registered nursing staff also highlighted the advanced clinical management and communication skills HCAs display during acute crises. For instance, an RN recounted an incident involving a middle-aged patient who deteriorated rapidly and began experiencing seizures while an auxiliary nurse was present in the home. The auxiliary successfully positioned the patient safely on his side. It simultaneously calmed the family by providing a clear, real-time explanation of the physiological event, maintaining stability until the registered nurse arrived to administer the necessary anticonvulsant medication (SP3P5, RN).

Hospice managers reinforced this view, stating that HCAs perform at a level equivalent to registered nurses when it comes to demystifying and normalizing the physiological process of death for frightened families. They noted that this presence reassures relatives that the transition is a natural one and ensures they do not feel abandoned during the process (S2P1, Manager).

In tandem with these routine duties, HCAs fulfilled an essential diagnostic function by assessing clinical indicators—such as constipation, respiratory changes, delirium, pain, nausea, and fatigue—that signal rapid physical or psychological decline. Notably, none of the interviewed HCAs reported using formal, structured

assessment scales to determine their course of action; instead, they relied on continuous, longitudinal observation of behavioral, verbal, and nonverbal indicators to shape their clinical responses.

HCA explained that because certain patients lose the capacity to articulate their physical distress, clinicians must remain hyper-vigilant. They noted that physiological signs like diaphoresis (sweating), physical restlessness, and altered respiratory patterns serve as vital cues. Experienced HCAs reported that years of professional experience enable them to intuitively identify discomfort, even when a patient verbally denies pain (S4P7, HCA).

This observation was echoed by other HCAs, who stated that the vast majority of family members lack the training to recognize when a relative is in pain. HCAs utilize their training to identify subtle facial grimaces and physical adjustments, making a significant diagnostic impact in domestic settings where families are often paralyzed by the fear of watching a loved one pass away (S6P4, HCA).

Within the structural framework of Hospice at Home programs, HCAs assumed a major role in pain mitigation, initially deploying non-pharmacological interventions such as psychological reassurance and physical repositioning. Both frontline HCAs and service coordinators acknowledged that these clinical assessments were highly complex, frequently ambiguous, and characterized by contradictory clinical signs. Nevertheless, managers, nurses, and HCAs agreed that the primary responsibility for initial clinical assessment and subsequent escalation of clinical concerns rested squarely on the visiting HCA.

Because the formal administration of controlled substances fell outside their legal scope of practice, HCAs were required to prompt family members to deliver prescribed analgesics. This operational boundary frequently forced HCAs to disturb exhausted relatives during the night to request that they medicate the patient. While some HCAs expressed relief at being legally insulated from medication administration, others expressed professional frustration, questioning how this boundary affected patient comfort, family strain, and public perception of their role and the wider service. Some participants challenged these systemic restrictions as counterproductive, noting a stark contradiction between home care and alternative settings, such as long-term nursing facilities, where HCAs possess delegated authority to administer medications.

One HCA articulated this legal frustration by pointing out the clinical irony of having pre-prescribed medications readily available in the home cupboard while being statutorily forbidden from drawing the dose into a syringe. Under current legislation, the task must be performed by the patient or a relative, a restriction that the worker viewed as an obstacle to proper practice, arguing that trained HCAs should legally be permitted to prepare, administer, and sign for the medication when a patient is in distress (S3P2, HCA).

Paralleling the management of the patient's physical decline was the requirement to address the acute emotional distress of family caregivers who were understandably anxious and uncertain. Maintaining such proximity to actively dying individuals and traumatized families was consistently linked to a high degree of occupational burnout and emotional exhaustion among HCAs. The data emphasized the severe emotional and ethical strain experienced by HCAs, particularly when attempting to manage refractory symptoms. The moral distress of navigating complex clinical decisions within the dying trajectory during out-of-hours shifts—and the resulting psychological toll—was widely recognized across HCA, nursing, and managerial cohorts.

An HCA described the intense psychological burden of managing a patient who becomes highly agitated, attempts to exit the bed, and cries out in pain. At the same time, the worker is entirely alone in the home. They noted that if all non-pharmacological options have been exhausted and emergency medical relief faces a two-hour delay, providing continuous reassurance under such conditions becomes exceptionally taxing, as the patient fundamentally requires immediate pharmacological breakthrough intervention (S1P5, HCA).

The long-term psychological residue of this work was noted by other HCAs, who remarked that the emotional gravity of these scenarios persists long after their shift ends. Staff frequently return home preoccupied with thoughts of the family and the patient's final hours (S4P7, HCA).

Specialist nurses corroborated this difficulty, explaining that the primary challenge for an OOH HCA lies in the solitary decision-making process of determining when to escalate a case for an emergency injection. They noted that the role demands a clinician who can maintain a tranquil environment and reassure anxious relatives that the dying process is unfolding normally, while simultaneously possessing the clinical acumen to escalate concerns the moment a crisis occurs (S3P3, Nurse Specialist).

Managers summarized this systemic vulnerability by observing that HCAs effectively serve as emotional sponges, absorbing profound trauma and distress daily, with overnight shifts and weekend periods presenting the most challenging environments (S5P2, Manager).

When standard non-pharmacological interventions failed to stabilize a patient's clinical condition, the sole responsibility for triggering a formal escalation of care rested with the HCA. The variable availability and logistical accessibility of back-up specialist services during the OOH window frequently compromised this procedural step. A portion of the HCA cohort reported having no direct, fast-track communications with specialist palliative networks overnight, meaning they had to instruct family caregivers to call standard emergency services to secure medical support. Conversely, other HCAs operated within models integrated with a broader specialist hospice network that provided rapid-response community teams, granting them direct communication channels

to specialist nursing personnel and emergency resources. Nonetheless, reports of clinical delays lasting between 1 and 4 hours before the arrival of professional reinforcement were common across all service designs.

An HCA recounted a challenging case where they immediately recognized a patient was actively dying, though the family remained unaware of the prognosis. Despite contacting the out-of-hours service early in the evening to account for unpredictable response times, the patient's terminal agitation escalated into heavy agonal breathing, and she passed away before the clinical reinforcement arrived. Consequently, the out-of-hours team arrived only in time to formally certify the death, rather than delivering the breakthrough medication that was critically needed earlier (S4P7, HCA).

Registered nurses reinforced these findings, noting that families regularly endure protracted delays during nights, weekends, and out-of-hours windows because on-call general practitioners rarely prioritize post-mortem verification of death. Nurses observed that some families are forced to wait over four hours with the deceased body, a scenario that induces profound distress. In these situations, the continuous presence of an HCA helps mitigate trauma, smooths the process for the family, maintains a dignified, intimate environment, and capitalizes on the deep therapeutic connection they have established with the relatives (S5P5, Nurse).

Under these conditions, HCAs frequently found themselves in situations where they had to prioritize monitoring the patient's clinical state while simultaneously navigating the frustration, sorrow, and psychological distress of the relatives. This dual burden fostered feelings of powerlessness and irritation among the auxiliary staff, with several noting that family members occasionally viewed them as inadequate, undermining their clinical confidence and prompting self-blame. When supplementary breakthrough analgesia was finally delivered, a registered nurse had to travel to the domestic setting to administer the injection. This structural division of labor enabled specialist nursing staff to focus on immediate clinical interventions for the patient, while the HCA focused on addressing the family's emotional needs.

In terms of interpersonal dynamics, frontline staff observed that patients frequently utilized their presence to discuss their underlying pathology because they wished to avoid causing distress to their adult children. Consequently, the arrival of the HCA provided a safe space where patients felt comfortable disclosing their feelings and speaking openly about their circumstances (S1P2, HCA).

Furthermore, HCAs detailed the challenges of managing refractory symptoms within short-staffed systems. One worker explained that when prescribed analgesics fail to provide relief, the immediate priority is to secure registered nursing support as quickly as possible. However, because community nursing teams are heavily understaffed, they are often detained with other local clients before they can respond. This delay results in prolonged periods during which the patient remains in severe pain or intense discomfort. Because HCAs are restricted from administering or modifying medications, they must wait for the out-of-hours nursing staff to arrive, a process that can take several hours and leaves the patient in a state of high distress by the time reinforcement arrives (S3P2, HCA).

The solitary nature of out-of-hours decision-making was also emphasized by auxiliary staff. An HCA explained that much of their hidden clinical judgment involves determining the precise moment to inform a family that the patient has entered the active dying phase. In the complete absence of a co-present doctor or nurse, the responsibility falls entirely on the HCA to evaluate the domestic environment and gauge how much prognostic information the relatives can process. This task is highly demanding because while some families possess the resilience to cope with reality, others risk becoming overwhelmed if bombarded with excessive information (S1P3, HCA).

Theme: Impact of HCAs within OOH care

Across all study locations, respondents reported that out-of-hours community hospice palliative services were fundamental to supporting patients and families within the domestic sphere. Participants highlighted several positive outcomes associated with this care, including preventing emergency hospital admissions, reducing reliance on residential care facilities, enhancing patient well-being, and reducing social isolation. Collectively, many informants recognized that OOH community palliative care played a substantial role in easing operational pressures across alternative NHS infrastructure. Crucially, all participants maintained that this intervention provided families with the structural support necessary to respect the patient's autonomy and fulfill their wishes to remain and pass away at home.

Administrative staff corroborated this point, with one manager noting that maintaining a patient in the home environment would be structurally unsustainable for families without the practical and physical support of a visiting staff member (S1P2, Manager).

Another coordinator emphasized that the presence of an HCA provides families with the rest and psychological reassurance that someone is actively monitoring the situation, thereby fostering a heightened sense of safety for the patient (S6P1, Manager).

Registered clinicians also noted the operational benefits of auxiliary integration. A nurse explained that while the arrival of a Marie Curie nurse is optimal due to their prescribing authority, having an HCA on-site still creates a

substantial reduction in the overall volume of emergency telephone calls received by the central service (S3P4, Nurse).

A prominent finding from both current and bereaved caregivers was an overwhelming sense of appreciation, with families placing a high premium on visits from hospice personnel to deliver necessary care. Although caregivers acknowledged that they frequently lacked a clear understanding of the specific clinical boundaries separating professional roles and that the influx of multiple workers into their homes was challenging, they identified numerous systemic benefits. Most notably, they felt supported in honoring their relative's explicit desire to die at home. Out-of-hours community services enabled these individuals to sustain their caregiving responsibilities by facilitating sleep, alleviating acute physical and emotional exhaustion, and bolstering their psychological well-being. As one caregiver described:

The provision of Hospice at Home support delivered the necessary reinforcement to allow me to remain present and care for my mother. This assistance granted me the opportunity to spend meaningful time with her that would have otherwise been impossible due to profound fatigue, which was severely threatening my own health. Before receiving this support, severe sleep deprivation had placed me on the verge of experiencing a seizure. However, because of this operational backing, my mother was able to realize her wish to pass away peacefully in her own home, which ultimately enhanced my ability to cope with her subsequent death (S4P9, Carer).

Interview data collected from service managers further illustrated how the HCA role mitigates severe caregiver burnout. One manager explained that this exhaustion could be alleviated either through direct respite care that allowed family members to sleep or through the psychological reassurance provided by the HCA's physical presence in the patient's room. For many HCA participants, a clear conceptual understanding of a 'good death' informed how they integrated family members into the terminal phase. This factor directly influenced the subsequent bereavement trajectory of the relatives.

An HCA expanded on this concept by stating that if a patient dies at home without experiencing a dignified and peaceful transition, the family is often left unable to process their grief healthily. Instead, their mourning is complicated by profound guilt, making the bereavement process significantly more difficult. Conversely, when a patient achieves a peaceful end, the relatives are better equipped to grieve and move forward. The worker noted meeting families months or a year down the line who were still struggling psychologically because the patient's terminal phase had been poorly managed (S1P3, HCA).

Managers reinforced this connection between the quality of death and subsequent psychological adjustment, noting that the presence of a support worker ensures the family receives the rest and reassurance required to feel secure. This intervention yields a positive knock-on effect during the bereavement phase, making grief more manageable because the family was able to fulfill their promise to keep their relative at home (S6P1, Manager).

Nursing staff similarly observed that the final moments of life leave a lasting impression on grieving relatives. If the transition is peaceful, it facilitates a smoother entry into the grief process, which is particularly vital for families who have never witnessed a death before and find the experience frightening (S6P3, Nurse).

The inclusion of HCAs was highly valued by both managers and clinical specialists, who viewed them as indispensable members of the out-of-hours community hospice framework, expanding service capacity and enhancing care delivery. HCAs were frequently characterized as the surveillance mechanism—the "eyes and ears"—of the out-of-hours community teams. Staff acknowledged that because these workers formed intimate relationships with patients and relatives, they often had deep insights into their unspoken needs and preferences. Through consistent information-sharing, HCAs optimized the delivery of appropriate interventions, initiated timely referrals for end-of-life planning and specialized equipment, such as syringe drivers, and enhanced communication across multidisciplinary teams.

A specialist nurse explained that HCAs effectively act as their nocturnal observers, providing detailed handovers regarding overnight developments and offering a comprehensive picture of the domestic situation. Cultivating trust is paramount, particularly during an active death, and the hospice would remain unaware of critical overnight changes without the continuous presence of the HCA (S6P3, Specialist Nurse).

This sentiment was supported by other nursing staff, who reiterated that having an HCA stationed in the home significantly decreases the influx of emergency phone calls directed to the on-call service (S3P4, Nurse).

Finally, HCAs were recognized as providing essential structural support, enabling wider hospice staff, district nurses, and general practitioners to execute core components of their roles within the out-of-hours framework. By managing the domestic environment, HCAs enabled registered clinicians to focus on alternative, complex caseloads. While certain stakeholders (including managers, HCAs, and specialist staff) acknowledged an operational overlap between HCAs' and registered nurses' responsibilities, they also highlighted the systemic inequity of auxiliaries performing these advanced duties without receiving equivalent financial remuneration or formal opportunities for professional advancement.

This investigation illuminates the critical nature of the HCA's contributions when viewed against the intricate operational obstacles and systemic hurdles that characterize the delivery of OOH community palliative services. Even though the development of community-based out-of-hours palliative care is widely advocated in the

literature [33, 34], compounding factors—such as escalating service utilization, pervasive clinical uncertainty, and limited structural assets—place immense strain on care delivery and frontline staff.

Corroborating previous academic research [7, 23, 28], these insights demonstrate that HCAs serve as the primary operational workforce in the OOH community palliative sector, offering a broad spectrum of physical interventions and emotional support to both patients and relative caregivers. Their clinical presence was deemed fundamental to mitigating family caregiver burnout and empowering patients to realize their autonomous preferences for remaining and passing away in their domestic environments. Furthermore, these results parallel historical data regarding the unmapped operational complexity and the shifting boundaries of the HCA role across the broader health sector [5, 54, 55]. Reflecting earlier empirical conclusions [16, 19, 21, 22], HCAs spend the most prolonged periods of direct contact with patients and relative carers, positioning them as the primary observers capable of identifying early signs of clinical deterioration that necessitate rapid intervention in community settings. During the out-of-hours window, this clinical complexity is exacerbated by the volatile nature of home-based settings, resource scarcity, and increasingly saturated organizational infrastructures [56]. This systemic vulnerability is further amplified because HCAs routinely operate as isolated field practitioners, navigating these environments with minimal access to real-time clinical mentorship or peer-led supervision [7]. These issues are compounded by structural barriers to accessing essential secondary resources—including immediate medical advice, specialist consultations, and prompt pharmaceutical supplies—during overnight and weekend hours. Consequently, these findings underscore the pressing need to optimize access to resources for field staff during out-of-hours periods to preserve responsive, safe palliative care delivery.

The empirical data compiled in this study expand the existing evidence base [19] by illustrating that HCAs are increasingly navigating highly volatile clinical scenarios in which they must assume diagnostic and monitoring responsibilities that were historically the exclusive domain of registered clinicians. The findings indicate that within the OOH framework, HCAs frequently shouldered the sole responsibility for tracking, analyzing, and translating physical symptoms, as well as for orchestrating the formal escalation of care. Nevertheless, managing this escalation process proved highly complex; workers frequently navigated a delicate balance between acute anxiety regarding the objective validity of the clinical need, a profound reluctance to disturb the patient's family, and the realistic awareness that substantial structural delays occurred before specialized reinforcement—such as rapid response units—could arrive on site. Both registered and unregistered staff groups articulated profound professional concerns about their ability to deliver high-quality end-of-life care within current systemic limitations, particularly the lack of fast-track access to specialist palliative guidance during out-of-hours shifts. These insights highlight an urgent requirement to implement structured clinical pathways and explicit decision-making frameworks tailored for out-of-hours field staff.

This operational reality raises significant questions regarding standard patient safety and the overarching quality of care delivered. Additionally, close attention must be paid to the psychological impact on family caregivers—who are forced to witness the physical and cognitive decline of their relatives while navigating protracted delays in securing professional assistance—as well as the psychological toll inflicted on the out-of-hours workforce. The findings of this project reinforce the conclusion that continuous interaction with terminal patients and traumatized relatives directly compromises HCA's psychological well-being, echoing previous academic literature [7, 42, 43]. This line of work demands intensive emotional labor, as HCAs must regulate and project appropriate affective responses within highly stressful clinical environments. Moreover, scenarios in which HCAs recognized a pressing clinical need but were restricted by narrow statutory authority or a lack of immediate resources indicate a high incidence of moral distress, highlighting a severe friction between recognizing an ethically sound intervention and being structurally prohibited from carrying it out. Adding to these operational pressures, historical nursing research identifies non-registered personnel as highly susceptible to vicarious trauma due to their routine exposure to distressing and terminal events [24-26]. This exposure can generate long-term psychological vulnerabilities [26]. Taken together, this evidence clearly establishes a mandate for organizational and structural reforms. While the boundaries of the HCA role will undoubtedly continue to shift, McPherson *et al.* [22] warn that this occupational evolution must not result in unregulated personnel taking on clinical duties beyond their appropriate scope of practice. Therefore, reinforcing institutional support mechanisms and establishing clear role definitions are essential steps to safeguard both the workforce's well-being and the quality of out-of-hours palliative services.

This investigation possesses several clear methodological strengths. To our knowledge, this project represents the inaugural study to empirically evaluate the precise role and clinical impact of the HCA within out-of-hours community palliative care frameworks. The research was informed by an extensive and varied participant cohort with rich professional experience spanning multiple tiers of organizational seniority, thereby capturing insights across a broad spectrum of care services. This comprehensive data collection enhances the overall credibility of our analytical conclusions. It provides a highly detailed perspective on the systemic challenges that characterize palliative care delivery outside standard daytime operations.

Conversely, several limitations must be acknowledged when interpreting this study. First, the generated insights rely on a predominantly white, purposively sampled cohort. At the same time, this approach is entirely congruent

with qualitative research designs. Still, it may not fully reflect the diversity of experiences across different geographic settings or distinct staffing groups. The specific perspectives of eligible individuals who declined to participate remain unmapped, and it is plausible that the volunteer cohort possessed particularly strong personal perspectives or distinct experiences that heavily shaped the derived themes.

Furthermore, significant recruitment obstacles—largely stemming from the systemic disruptions of the COVID-19 pandemic, heightened operational pressures on services, and broader contextual barriers—prevented the direct inclusion of active patients within this research. Second, the investigation was embedded within a distinct organizational and geographic framework. This factor may restrict the immediate transferability of these insights to alternative palliative settings, particularly those utilizing divergent staffing models, unique referral pathways, or different out-of-hours structural arrangements. Notably, four of the analyzed services operate within Northern Ireland, which maintains an independent health and social care infrastructure distinct from the remainder of the United Kingdom.

Conclusion

In summary, this study emphasizes the systemic complexity of managing out-of-hours community palliative care and underscores the expansive, shifting responsibilities assigned to unregulated HCAs within this domain. HCAs provide foundational support to dying individuals, relative caregivers, and wider out-of-hours networks while operating under severe resource constraints, high service pressures, and minimal direct oversight. They are routinely exposed to acute patient and family trauma, resulting in a substantial psychological burden that requires immediate organizational acknowledgment and structural support to preserve both employee well-being and the quality of clinical care. These conclusions contribute to the expanding body of empirical literature calling for the implementation of a formal statutory regulatory framework for HCAs, while highlighting the need for a deeper understanding of out-of-hours palliative delivery models. Future academic research is strongly recommended to investigate further the changing operational boundaries of the HCA workforce and to evaluate their broader implications for safe, long-term care sustainability.

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