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Exploring the Role and Contribution of Healthcare Assistants in Out-of-Hours Palliative Care: A Mixed Methods Protocol

Annie Marcela Vivares-Builes[1*], **Irina Morales**[1]

[1]*Department of Education, Universidad del Norte, Barranquilla 0000, Colombia.*

Abstract

A large proportion of people spend their final year of life at home, with many expressing a preference to die there. However, this often requires access to care beyond normal working hours. Out-of-hours palliative services, typically delivered by multidisciplinary teams that include Health Care Assistants (HCAs), play a vital role in supporting patients and families. Despite this, there is limited understanding of how HCAs contribute to these services and influence patient care. This study aims to explore and clarify the role, input, and impact of HCAs in out-of-hours community palliative care provided by hospice organisations. This exploratory investigation adopts a mixed methods design comprising four interconnected stages. Stage one will conduct a scoping review to chart existing evidence and policy related to the HCA role in out-of-hours palliative care and to identify areas of limited knowledge. Stage two involves a UK-wide online census of hospices to describe variations in service models and define the nature of HCA involvement. Stage three will undertake multiple organisational case studies across representative service types, gathering both qualitative and quantitative data from HCAs, patients, carers, and service managers to understand practice and experiences in context. Stage four will integrate and refine the findings through a series of online focus groups. Ethical approval for phase two has been granted by the Ulster University Research Governance Filter Committee (Nursing and Health Research). The study's findings will be shared through academic publications, conference presentations, and professional networks, including social media channels.

Keywords: Health Care Assistant, Palliative Care, Out-of-Hours Services, Mixed Methods, Hospice, Community Care

Introduction

Most individuals spend the majority of their final year of life at home, regardless of where death ultimately occurs [1, 2]. Even with effective advance planning, unforeseen deterioration can occur, leading patients and family caregivers to seek out-of-hours (OOH) support [3, 4]. In the United Kingdom (UK), OOH care encompasses services provided between 18:30 and 08:00 on weekdays, as well as throughout weekends [5]. Recent evidence underscores the essential role of OOH palliative services in ensuring quality end-of-life care [6]. Indeed, it is estimated that approximately 30% of palliative care patients require OOH services during their final days of life [7]. Despite this, research examining OOH palliative care remains limited [8], with persistent concerns reported around patient safety, timely access to care, medication management, availability of clinical information, and the competence and confidence of OOH care teams [5]. OOH care is delivered by multidisciplinary teams that may include general practitioners (GPs), district nurses, specialist palliative care nurses, and Health Care Assistants (HCAs), all of whom possess varying levels of training and experience in end-of-life care. HCAs—also referred to as nursing auxiliaries or support workers—are not professionally regulated and lack national training standards, yet they play a crucial role in providing hands-on palliative support in the home [9–11].

Corresponding author: Annie Marcela Vivares-Builes
Address: Department of Education, Universidad del Norte, Barranquilla 0000, Colombia.
E-mail: ✉ annie.vivaresbuiles94@gmail.com

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Existing research highlights that HCAs are central to the provision of chronic and end-of-life care [12–16], often delivering the majority of direct care [15] and serving as the first to recognise and communicate patient changes to other professionals [17, 18]. Within the home setting, HCAs frequently act as intermediaries between families and healthcare providers, offering emotional reassurance, guidance, and practical support up to and including the time of death [12, 19]. Nevertheless, many HCAs report feeling insufficiently prepared for the complexities of chronic and palliative care [20, 21].

While the roles of other members of the OOH palliative team have been explored [4, 22–24], the specific contribution and impact of HCAs within hospice-based OOH services remain under-researched. Despite being rarely acknowledged as core members of the palliative care team [20, 25, 26], evidence indicates that HCAs form a highly valuable part of the workforce, making significant contributions to the quality and continuity of OOH palliative care [12, 14, 16]. Gaining a more comprehensive understanding of their role across varying UK service models could enhance multidisciplinary collaboration and support policy development to help more patients remain at home at the end of life.

The COVID-19 pandemic has placed exceptional demands on health and social care systems, while simultaneously restricting opportunities for in-person research. In response, data collection strategies for the present study have been adapted to align with both ethical and methodological standards during periods of public health restrictions, ensuring safety while maintaining research integrity.

Materials and Methods

A mixed methods approach will be employed, combining both qualitative and quantitative techniques to explore the research problem within its real-world context [27]. This design enables a more comprehensive understanding of complex, practice-based phenomena such as the role of Health Care Assistants (HCAs) in out-of-hours (OOH) palliative care. The study will primarily follow an explanatory sequential design, which involves initially collecting and analysing quantitative data, followed by a qualitative phase that builds upon the earlier results to refine research questions, guide sampling, and inform subsequent data collection [27]. While this sequential structure underpins the study, exploratory elements will also be incorporated to further investigate unexpected findings and address inconsistencies across data sources [28, 29].

Given the study's aim to generate a deep understanding of the HCA role in OOH palliative care, the qualitative components will hold greater prominence. A pragmatic paradigm will guide the research, embracing the use of both quantitative and qualitative assumptions and methodologies as appropriate to the research question [30]. Integration of data will occur within and across study phases through data transformation and typology development techniques [31]. Full integration will be achieved once all phases are completed, using approaches such as data matrix mapping [32], following the thread [33], and critical interpretive synthesis [27] to merge insights into a cohesive interpretation. The study consists of four interconnected phases.

Phase 1: Scoping review

The first phase will involve conducting a scoping review of relevant policy documents and academic literature to systematically map existing evidence and identify knowledge gaps concerning the HCA role in OOH palliative care [34]. To date, no published synthesis has comprehensively integrated empirical studies and grey literature to capture the breadth and complexity of this topic [35].

To ensure rigour and transparency, the review will follow the six-stage framework proposed by Arksey and O'Malley [36] and refined by Levac *et al.* [37], comprising:

1. Identifying the research question: Developed collaboratively with the research team and stakeholders (e.g., *What are the roles, responsibilities, and contributions of HCAs in OOH palliative care?*).
2. Identifying relevant studies: Searches will be conducted across major electronic databases (CINAHL, MEDLINE, EMBASE, PsycINFO) using predetermined inclusion criteria, supplemented with grey literature searches (e.g., Web of Science Conference Proceedings, Grey Literature Report, OpenGrey). Search strategies and terms will be developed in collaboration with stakeholders, the research team, and a specialist librarian. Searches will include both keyword and subject heading terms (e.g., MeSH) and will be limited to English-language publications from the past 10 years.
3. Study selection: Two reviewers will independently screen titles, abstracts, and full texts. Discrepancies will be resolved through discussion or consultation with a third reviewer.
4. Data extraction: A structured data extraction template will be designed based on study aims to capture study characteristics and relevant findings. The template will be piloted and refined through consultation with the research team and stakeholders.
5. Data summary and synthesis: Key concepts, evidence types, and knowledge gaps will be mapped to provide an overview of existing research and policy landscapes.

6. Consultation: A patient-partner will act as an advisor throughout the process to ensure that the patient and caregiver perspective is represented. Stakeholders and subject experts will also contribute to refining the search approach and interpretation of findings.

Findings from this scoping review will inform the design and direction of subsequent phases, establishing a conceptual foundation for the overall study.

Phase 2: Quantitative component – Survey of UK hospices

The second phase will comprise a nationwide census of hospices across the United Kingdom, employing a cross-sectional survey design. This stage aims to develop a typology of out-of-hours (OOH) services and to examine the characteristics of the Health Care Assistant (HCA) workforce, including their roles, contractual arrangements, and the organisational and regulatory frameworks governing community-based OOH service delivery. The findings will establish a national overview of HCA involvement in hospice-led OOH care and will form the sampling frame for case study selection in the third phase.

The target population will include Directors of Nursing or Community Nursing Services Managers responsible for workforce planning and service delivery in adult hospices across the UK. A total of 260 services were identified from the *Hospice UK Service Directory* (retrieved November 2017), and one representative from each organisation will be invited to participate. A power calculation based on a 95% confidence level, a 5% confidence interval, a 50% response distribution, and a population size of 260 indicates a required sample of 156 respondents, allowing for a 40% non-response rate [38].

Data will be collected through an online, self-administered questionnaire designed in accordance with best practice guidelines for survey development [39, 40]. This approach enables efficient and cost-effective data collection across geographically dispersed sites. The questionnaire, informed by findings from Phase 1, will include a combination of closed and open-ended questions and will cover four key areas: service typology and models of practice; HCA workforce composition, training, and role in home-based OOH care; organisational characteristics such as size, funding status, and population served; and the impact of the COVID-19 pandemic on OOH service delivery and the HCA role. The instrument will undergo pilot testing by a panel of experts in hospice and palliative care to assess clarity, relevance, and face validity before dissemination.

Hospices will first be contacted by telephone to identify the most appropriate respondent, typically a senior member of staff such as the Director of Nursing or Community Nursing Services Manager. An email invitation containing a hyperlink to the online survey and an opt-out option will then be distributed. Participants will have three weeks to complete the questionnaire, with reminder emails sent after one and two weeks respectively to maximise response rates. The survey will close after four weeks. Completion and submission of the questionnaire will constitute implied consent to participate.

Data will be cleaned and analysed using SPSS version 23. Descriptive statistics will be produced, and the normality of distribution assessed. Open-ended responses will undergo content analysis to identify key categories and themes that may lend themselves to further quantitative examination. Response rates and methodological quality will be reported in line with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines [41]. The results of this phase will inform the sampling matrix for Phase 3 and guide the identification of priority areas for in-depth qualitative investigation.

Phase 3: Qualitative component – Organisational case studies

The third phase will build upon the national survey findings to explore in greater depth the role, contribution, and impact of HCAs in community-based OOH hospice services. A qualitative multiple case study design will be adopted to achieve a rich and contextualised understanding of practice. Case sites will be purposively selected to reflect the diversity of service typologies identified during Phase 2.

This phase seeks to generate detailed insights into how HCAs contribute to OOH palliative care delivery and how their involvement supports patients and families to remain at home at the end of life. Data will be collected from multiple perspectives, including HCAs, patients, family caregivers, and service managers, in order to capture the complexity of interactions within multidisciplinary teams and to understand how different service configurations shape experiences of care.

Population and sample size calculation

A purposive sampling strategy will be adopted to identify up to six organizational case studies of out-of-hours (OOH) hospice services drawn from phases one and two of the study [42]. The criteria for selecting these cases will be shaped by the earlier findings but are also defined in advance to ensure representation of diverse service models. The sample will include different configurations of community-based OOH palliative care, such as Rapid Response Teams, Hospice at Home programs, and Night Nursing Services. Each participating service will have a multidisciplinary team structure, with healthcare assistants (HCAs) actively involved in care delivery. Every service model will be represented by at least one case study, and each OOH service will act as a separate unit of analysis. To capture variation across settings, maximum variation sampling will be applied using information from phase two (survey), ensuring that selected sites differ in their use of HCAs, service size, and geographical location. This approach will enable exploration of how different OOH hospice service models operate within their specific contexts and provide insight into the range of stakeholder experiences.

Data collection

Drawing on Yin's case study methodology [43], a mixed-methods approach will be employed to explore the role and contribution of HCAs within OOH palliative care services. Data collection will combine semi-structured interviews with documentary analysis to build a rich, contextual understanding. The primary method will involve semi-structured interviews conducted online via platforms such as Zoom or Skype, each lasting approximately 30 to 60 minutes. Telephone interviews will also be offered when preferable for participants. Interviewees will include patients, family caregivers, HCAs, other healthcare professionals, and senior managers connected to each hospice service. Conversations with patients and caregivers will focus on how HCAs contribute to care delivery and patient support. Interviews with HCAs will examine their training, experiences, and responsibilities, while discussions with other professionals will capture perceptions of the HCA role, its influence on service quality, and working relationships within the team. Senior managers will be invited to discuss service organization, the integration of HCAs, and any training or structural factors that influence care provision. Interview schedules will be informed by the study's objectives and findings from earlier phases, and all materials will be piloted at a hospice not involved in the research. To complement interview data, site-level documents such as policies, service descriptions, and materials outlining the HCA role will be reviewed. Additional socio-demographic and epidemiological information for each locality will also be analyzed to contextualize the case studies.

Recruitment and informed consent

Before data collection begins, a principal liaison person [44] with a thorough understanding of each service will be identified and briefed about the study. This individual will act as the main point of contact for the research team, helping to facilitate recruitment and providing background information on the service setting. Once recruitment is underway, individual interviews will be conducted with patients, caregivers, HCAs, other healthcare professionals, and senior management staff. These will take place online (via Skype or Zoom) or by telephone, depending on participants' preferences. From each hospice site, a purposive sample [45] of approximately two to four patients and caregivers who meet the inclusion criteria will be invited to participate. Patients who agree to take part will be asked to nominate a family caregiver, and both will be interviewed separately to discuss their experiences of the HCA role in care delivery. These interviews will be followed by discussions with one to three HCAs and three to five members of the multidisciplinary OOH team, which may include general practitioners, district nurses, specialist palliative care nurses, or other relevant professionals such as social workers. Additionally, two to three senior managers or service coordinators will be interviewed at each site. Because qualitative research emphasizes depth over quantity, the exact sample size will depend on when data saturation is reached—that is, when no new themes or insights are emerging [46]. All interviews will be arranged at times convenient for participants, and a brief demographic questionnaire will be used to collect background information.

Inclusion criteria: Case studies

Participants for the case study phase will be recruited according to the following eligibility criteria. Patients must be receiving community-based palliative care, be aged 18 years or older, judged by their healthcare professional to be physically and cognitively capable of participating, and willing to provide informed consent. Caregivers must also be over 18 years of age, nominated by the participating patient, able to take part both physically and mentally, and willing to consent. Healthcare assistants (HCAs) must be currently employed in the delivery of out-of-hours (OOH) palliative care within community settings, aged 18 years or older, and willing to give consent. Healthcare professionals (HCPs) must be generalist or specialist practitioners in palliative care who consent to take part. Finally, managers must hold a senior leadership role within the hospice, have oversight of OOH service delivery and/or management of HCAs, and provide informed consent.

Data analysis

All interviews will be audio-recorded digitally with participants' written consent and subsequently transcribed verbatim. Data will be analyzed using a framework approach to allow systematic comparison both within individual case studies and across different cases [47]. During phase three, the data will be drawn from several sources—including patients, caregivers, and healthcare professionals—allowing for a comprehensive, multi-perspective understanding of each case. The within-case analysis will focus on developing an in-depth picture of each service, while the cross-case analysis will identify overarching themes, shared patterns, and contextual distinctions unique to particular sites [44]. Themes emerging from secondary data sources will also be examined to highlight contextual and organizational factors that may influence findings.

Phase 4: Online focus groups

Goal

The final phase of the study will involve online focus groups designed to encourage reflection and collective discussion of the findings. Insights from these discussions will inform the development of practical and strategic recommendations regarding the HCA role within community-based OOH palliative care services.

Population and sample size calculation

A purposive sampling strategy will be used to recruit key stakeholders to participate in four focus groups, each comprising approximately five to eight participants. Initial participants will include eight to ten individuals who contributed to the phase three case studies and have in-depth knowledge of the HCA role and OOH community palliative care—such as HCAs, senior managers, and other healthcare professionals. To ensure a broad range of perspectives, additional participants will be recruited using purposive snowball sampling. This will include patients (with appropriate support to participate), family caregiver representatives (approximately six to eight individuals), service managers (around three to four), and policy makers (three to four).

Data collection

Focus group participants will be drawn from all four UK jurisdictions—England, Scotland, Wales, and Northern Ireland—to ensure geographic and policy diversity across the British Isles. Each focus group is expected to last between one and one and a half hours, at a time agreed upon with participants. Sessions will be held online using videoconferencing platforms such as Zoom or Skype. While traditional in-person focus groups are often valued for generating deeper insights through face-to-face interaction [48, 49], it has been noted that virtual formats may limit some aspects of group dynamics [50]. However, existing evidence suggests that the richness and quality of data produced in virtual discussions can be comparable to that of in-person focus groups [51, 52].

Over and above the risks associated with face-to-face focus groups such as lack of participation, or one person dominating, [48] there are also risks specifically associated with online focus groups. These include – participants lack of knowledge about the use of technology; unsuitable environments resulting in distractions or interruptions (from colleagues or family); privacy and confidentiality issues.

In the present study several measures will be used to mitigate against such issues. For example, for participants who are unsure of the online environment, training and a test call will be offered. Specific information included in the Participant Information Sheet, and Consent Form, such as the importance of securing a private space for the duration of the focus group, may help to appraise participants of the online process and expectations [53]. In addition, participants will be asked, if possible, to wear headphones in order to ensure confidentiality [52].

Data analysis

Quantitative data will be gathered through questionnaires designed to capture participants' sociodemographic characteristics, as well as their experiences and attitudes toward the role of healthcare assistants (HCAs) in out-of-hours (OOH) community palliative care. The questionnaires will include both open-ended and Likert-scale items to elicit a broad range of responses. With participants' consent, focus group discussions will be audio-recorded, transcribed verbatim, and analyzed thematically [54] to identify key concepts and recurring patterns. The analysis will highlight issues that stakeholders regard as significant and will inform the development of strategic recommendations for strengthening the HCA role within OOH palliative care services.

Patient and public involvement

A patient partner has been actively involved throughout the research process, serving as a consultant to ensure that the perspectives and experiences of patients are accurately represented and meaningfully integrated into the study design and interpretation.

Ethics and dissemination

Ethical approval for phase two of the study has been obtained from the Ulster University Research Governance Filter Committee (Nursing and Health Research). Approvals for subsequent phases will be sought sequentially, in accordance with institutional research governance procedures and ethical guidelines. All participants will receive an information sheet outlining the study's purpose, background, and ethical considerations, including confidentiality and data protection.

In phase two, the return of completed questionnaires will be taken as implied consent. For phases three and four, written informed consent will be obtained from all participants before data collection begins. Confidentiality and secure data handling will be maintained throughout. Questionnaire responses will remain anonymous, and all interview data will be de-identified; participants will be assigned unique codes accessible only to the research team. Data storage, management, and disposal will comply fully with current data protection legislation [55].

Dissemination plan

A comprehensive dissemination strategy has been developed using the Evidence-based Model for the Transfer and Exchange of Research Knowledge (EMTReK) in Palliative Care [56]. This framework supports effective knowledge exchange among multiple stakeholder groups through tailored communication approaches. The main audiences for dissemination include academics, practitioners in palliative and end-of-life care, service commissioners, community nursing providers, patients, caregivers, and members of the public. A multi-modal dissemination strategy will be employed, incorporating written, oral, and digital communication channels throughout the study and upon completion.

Written dissemination

Participating hospices from phase three will receive ongoing updates throughout the study, which will be shared with staff through newsletters and with the wider community via social media. A full report of the study findings and a plain English summary designed for public and patient engagement will be published online and made accessible to all participants. Findings will also be submitted to peer-reviewed academic and practice-based journals to reach diverse audiences. The research team will further produce public-facing materials such as newsletters, plain-language summaries, and blog posts to enhance accessibility and engagement.

Oral presentations

Abstracts summarizing the research findings will be submitted to national and international conferences, including the Hospice UK Conference and the European Association of Palliative Care Congress. Presentations will also be delivered to health service managers and organizational leaders responsible for community-based OOH services and HCA workforce management, focusing on the practical and policy implications of the findings.

Social media dissemination

Social media platforms, including YouTube and X (formerly Twitter), will be used to share updates and key outcomes in an accessible and engaging format. Dissemination will occur through Ulster University's institutional channels as well as a dedicated project account established specifically for this study.

Public engagement

To maximize outreach and ensure that findings benefit the broader community, partnerships will be maintained with organizations such as Marie Curie, the National Council for Palliative Care, and Dying Matters. These collaborations will facilitate the sharing of results with the public and promote dialogue about the role of HCAs in OOH community palliative care.

Abbreviations

HCA: Healthcare assistant
OOH: Out-of-hours
PC: Palliative Care

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