Journal of Integrative Nursing and Palliative Care (JINPC)

Original Article

Volume 7 | Issue 1 | Page 64-75

Exploring the Acceptability of Lay-Carer Administration of Anticipatory Injectable Medications in Home-Based End-of-Life Care

Karolina Novak[1]*, Tomasz Wrobel[1]

[1]*Department of Nursing and Supportive Care, Faculty of Health Sciences, Jagiellonian University, Krakow, Poland.*

Abstract

Global data indicate that the majority of individuals prefer receiving end-of-life care and dying in their own homes, provided the care is of high quality. Nonetheless, this objective is frequently obstructed by systemic and logistical barriers. Palliate represents a nurse-guided intervention designed to overcome these obstacles. It equips lay-carers to administer end-of-life subcutaneous injections to their relatives by providing targeted training, instructional materials, and structured documentation. To examine how patients, informal caregivers, and healthcare providers perceive and experience the acceptability of the Palliate intervention via the Theoretical Framework of Acceptability (TFA), while identifying perceived obstacles and facilitators to its execution. Guided by the TFA, a qualitative investigation was executed utilizing semi-structured interviews with healthcare practitioners, patients, family carers, and policy-makers. The gathered data underwent deductive thematic analysis. Perspectives on the acceptability of this end-of-life intervention were gathered from thirty participants, comprising individuals diagnosed with advanced progressive illnesses, family caregivers, and various healthcare professionals working in palliative care. Respondents highlighted several potential advantages, such as improved symptom management, shorter delays in medication delivery, and greater empowerment of families providing home care. Conversely, apprehensions were voiced regarding caregiver burden, emotional strain, and the necessity of clinical supervision. A segment of the sample was drawn from direct practical experience in deploying or assisting with the intervention, offering valuable insights into both its functional utility and operational challenges. Although the Palliative intervention was broadly perceived as acceptable and potentially advantageous, expanding its implementation demands meticulous planning. Acceptability depended heavily on caregivers receiving structured training, continuous professional support, and participating on a purely voluntary basis. These outcomes shed light on the boundaries of informal caregiving and carry clear implications for incorporating family-led end-of-life medication management into health systems. Before recommending wider clinical adoption, additional research is required to assess its safety, outcomes, and feasibility across diverse environments.

Keywords: Palliative care, Qualitative research, Person-centered care, Human-centered design, Innovation

Introduction

Over recent decades, strategic policies for end-of-life care have increasingly emphasized enabling individuals to pass away in their place of choice, most often their own home [1-3]. This strategic direction aligns not only with the expressed desires of numerous patients and their relatives [4, 5] but also with broader healthcare objectives aimed at decreasing preventable hospitalizations and elevating the standard of palliative care [6-8].

An umbrella review found that, globally, the home is the most favored environment for end-of-life care among both patients and family members, and the preferred site of death (51%–55% in meta-analyses) [9]. Yet, despite these definitive preferences for dying at home, the actual location of death frequently deviates from these wishes, with alignment rates ranging wildly from 21% to 100% [9]. Consequently, a large number of individuals die

Corresponding author: Karolina Novak
Address: Department of Nursing and Supportive Care, Faculty of Health Sciences, Jagiellonian University, Krakow, Poland.
E-mail: ✉ karolina.novak@gmail.com

Received: 14 November 2025; **Accepted:** 27 February 2026; **Published:** 30 June 2026

How to Cite This Article: Novak K, Wrobel T. Exploring the Acceptability of Lay-Carer Administration of Anticipatory Injectable Medications in Home-Based End-of-Life Care. J Integr Nurs Palliat Care. 2026;7(1):64-75. https://doi.org/10.51847/4dGObKtGgN

within hospital wards, encountering avoidable distress, unwanted clinical interventions, and, in certain instances, elevated economic costs [10-14].

A well-documented obstacle to securing a home death is the prompt delivery of symptom-relieving therapies (e.g., for pain, nausea, and other distress), particularly during the final hours or days of life. These therapeutic agents typically necessitate subcutaneous or intravenous delivery, given that many individuals nearing death cannot manage oral medications [15, 16]. Within the domestic setting, subcutaneous delivery represents the most viable option, as it avoids the need for invasive intravenous access [17].

Traditionally, the administration of subcutaneous medication in a patient's private home has been the responsibility of a district or community nurse [18]. Nevertheless, disparities in staffing resources, geographic constraints, and limited out-of-hours service delivery regularly lead to delays and impede timely access to essential medications—factors that negatively affect a patient's quality of life and the standard of end-of-life care [19-21].

Numerous approaches have been proposed to mitigate this issue [15, 16, 22, 23]. In the UK, for instance, an increasing number of NHS Trusts have trialed interventions that authorize trained informal caregivers to give 'as required' (PRN) subcutaneous injections at home [24, 25]. These strategies are designed to ensure more rapid symptom control, alleviate distress for patients and their families, and lower the frequency of emergency admissions or urgent professional call-outs [26, 27].

Data originating primarily from Australia has shown that family administration of subcutaneous end-of-life drugs can be viable, acceptable, and advantageous when the right conditions are met [28-30]. Interest in these strategies is rising within the UK [31-33], and certain Trusts have formulated localized guidelines and operational structures to implement this practice [34, 35]. Even so, widespread national deployment remains constrained, and evidence concerning the acceptability, safety, and ultimate outcomes of these protocols within the UK healthcare context is still developing [31].

The Palliate intervention (henceforth termed 'Palliate') represents one such model, adapted from an established program of lay-carer managed palliative care utilized in Wales [36]. Palliate is a nurse-led, formalized intervention that provides training, instructional resources, and documentation to assist informal caregivers in administering anticipatory subcutaneous injections to their family members during end-of-life care; it is currently being deployed within a prominent London NHS Foundation Trust.

This investigation addresses two of the most critical priorities for palliative and end-of-life care highlighted by the James Lind Alliance Priority Setting Partnership [37]: (1) how to optimize the delivery of palliative care outside standard working hours to avert crises and help patients remain in their preferred care setting, and (2) what specific information and training family members require to deliver safe, competent care at home, including managing medications. Within this framework, this study examines the challenges and prospects associated with Palliate. By engaging directly with patients, caregivers, and clinicians, this research aims to identify the outcomes of greatest significance to stakeholders, thereby informing improvements to the intervention and guiding the setup of a future definitive clinical trial.

Materials and Methods

Study design

This project employed an exploratory, qualitative design, using semi-structured interviews to elicit detailed perspectives from diverse stakeholders. The study framework was guided by the Theoretical Framework of Acceptability (TFA), which functioned as both the conceptual foundation and the analytical template [38, 39]. It offers a systematic, theory-driven methodology for analyzing how acceptable an intervention is perceived to be by the individuals who either deliver or receive it.

The TFA comprises seven primary dimensions: affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, and self-efficacy [39]. These distinct domains structured both the formulation of the data collection instruments and the subsequent analytical steps. Utilizing the TFA maintained conceptual uniformity throughout data collection and analysis, allowing for an organized evaluation of core acceptability dimensions while leaving room for inductive insights to emerge outside the predefined categories.

The central research question directing this investigation was:

What are the viewpoints and experiences of patients, informal caregivers, and healthcare professionals concerning the acceptability of lay-carer administration of anticipatory subcutaneous medications in the home setting?

The execution and reporting of this study adhere strictly to the COREQ guidelines outlined in the COREQ (COnsolidated criteria for REporting Qualitative research) Checklist [40].

Participant sampling and recruitment

As part of the operational framework, purposive sampling was utilized to select participants from four distinct stakeholder categories: Healthcare Professionals, Service Leaders and Policy Stakeholders, Informal Carers, and Patients. The recruitment strategy aimed for roughly 3–5 respondents per category (totaling approximately 25–30 individuals), to incorporate professionals whose positions align with those typically engaged in end-of-life care, according to NHS definitions [41]. Adhering to the principles of qualitative research [42, 43], the enrollment process was continually assessed throughout the investigation, with final sample sizes determined by data richness and the point at which no novel themes emerged (i.e., thematic saturation).

Enrollment was conducted in the UK through established professional networks and focused campaigns on social media platforms (such as Twitter, Facebook, and LinkedIn), as well as in digital spaces dedicated to palliative care practice communities. At an operational site implementing the Palliative intervention, a clinical specialist nurse, connected to a regional NHS research network, also assisted in locating and inviting prospective respondents. To capture both well-informed and uninitiated viewpoints, individuals were eligible regardless of whether they had previous knowledge of the Palliate program. Eligible candidates were required to be 18 years of age or older and proficient in English communication.

Data collection

The research team formulated a semi-structured topic guide based on the TFA to ensure alignment with core dimensions, including affective attitude, burden, and perceived effectiveness. This tool was engineered to preserve consistency across all interview sessions while maintaining the flexibility to pursue novel themes as they emerged in participant narratives. It addressed primary areas, including the respondents' baseline reactions to the intervention concept, perceived advantages and obstacles, anticipated emotional or functional burdens, and environmental factors shaping overall acceptability (Appendices 1–3).

The dialogues were held virtually via Microsoft Teams and audio-recorded after informed consent was obtained. Sociodemographic details were collected via a concise online survey administered via Qualtrics [44] and summarized descriptively. Data collection was maintained until thematic saturation was reached.

Data analysis

The audio records were transcribed word-for-word and stripped of identifying information. These text files were then transferred into NVivo 15 [45] to facilitate coding and evaluation. A deductive, thematic framework approach was applied, structured around the dimensions of the TFA, to systematically and theory-drivenly assess the program's acceptability. Initially, the transcripts were coded using a structural grid derived from the seven TFA domains (affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, and self-efficacy). Although the overarching strategy was deductive, the coding protocol remained receptive to inductive discoveries to capture unanticipated yet meaningful nuances within the TFA categories.

Age data was gathered using categorical intervals. To compute the mean and standard deviation (SD), the central value of each age interval was utilized to approximate the participants' ages. Consistent with a deductive framework, the seven TFA domains served as the primary analytic themes; no supplementary subthemes were established. Divergences within each category (obstacles and enablers) are detailed narratively alongside illustrative extracts. The development of themes occurred through continuous group discussions, and coding variations were resolved through consensus. To strengthen validity and minimize interpretive bias, early analyses were examined by an independent investigator. A portion of the transcripts underwent parallel coding, with any differences resolved collaboratively to maintain uniformity when utilizing the conceptual grid.

Rigor and trustworthiness

To maintain analytical rigor, the project adhered to fundamental quality benchmarks for qualitative inquiry, including investigator reflexivity, the preservation of an audit trail, and cyclical theme verification [46, 47]. The trustworthiness of the findings was established through the application of Guba and Lincoln's four dimensions of qualitative rigor. Credibility was reinforced through the deployment of multiple coders, broad participant representation, and recurrent team debriefings to validate interpretations. Dependability was sustained through an extensive audit trail documenting all methodological and analytical choices, including coding iterations, theme generation, and reflexive journals. This audit history was examined by the core research group and reviewed alongside an independent study steering committee to optimize the clarity and uniformity of the analytical workflow. Confirmability was protected through peer reviews and persistent group reflexivity to counteract personal bias and maintain operational transparency. Finally, transferability was facilitated by rich contextual descriptions and open reporting, which enabled meaningful comparisons across alternative environments.

Researcher characteristics and reflexivity

The investigating panel comprised a multidisciplinary group, featuring scientists specializing in public health, registered nurses with hands-on palliative experience, specialist palliative physicians, and scholars focused on end-of-life care research. This combination of expertise fostered deep collaboration and integrated varied clinical, public health, and academic viewpoints into the project. The investigators responsible for conducting and evaluating the interviews remained cognizant of potential biases arising from their distinct career paths. To manage this, uniform interview schedules were used to ensure consistency, and the group engaged in sustained dialogue and reflexive practices throughout all stages of the thematic analysis.

Results and Discussion

Thirty individuals—comprising patients, informal caregivers, pharmacists, registered nurses, general practitioners (GPs), service commissioners, and clinical directors—participated in a qualitative interview **(Table 1)** between October 2024 and April 2025. The demographic attributes of the sample are consolidated in **Table 2**.

Table 1. Key stakeholder groups. From: Acceptability of supporting lay-carer administration of anticipatory subcutaneous medications at home: a qualitative study using the theoretical framework of acceptability.

Key stakeholder category	Stakeholder subgroup	Number of participants
Healthcare professionals	Palliative care/end-of-life care nurses	3
	District nurses	3
	General practitioners (GPs)	3
	Palliative care/end-of-life care physicians	2
	Non-medical prescribers (pharmacists)	3
Service leaders and policy stakeholders	Former National Clinical Director of a palliative/end-of-life care charity, National Director of a palliative/end-of-life care charity, National Clinical Lead for End-of-Life Care, Public Health Professional, and ICB Commissioner	5
Informal carers	Family or lay carers with firsthand experience of using Palliative	3
	Family or lay carers without prior experience of using Palliate	5
Patients	Individuals diagnosed with advanced illness, all of whom had no experience using Palliate	3

Table 2. Participant demographics. From: Acceptability of supporting lay-carer administration of anticipatory subcutaneous medications at home: a qualitative study using the theoretical framework of acceptability.

Characteristics	Healthcare professionals, service leaders, and policy stakeholders	Informal carers and patients
Gender, n (%)		
Male	5 (26%)	5 (45%)
Female	14 (74%)	6 (55%)
Age (years)		
Mean (SD)	52 (11)	58 (17)
Ethnicity, n (%)		
White British	18 (95%)	10 (91%)
Asian or Asian British – Indian	1 (5%)	1 (9%)
Educational attainment, n (%)	All participants held an undergraduate or postgraduate degree: 19 (100%)	Informal carers: Undergraduate or postgraduate degree: 7 (87.5%); Vocational or technical qualification: 1 (12.5%). Patients: Undergraduate or postgraduate degree: 2 (66.6%); A-Levels or equivalent qualification: 1 (33.3%).
Professional role/Position, n (%)	Palliative care/end-of-life care nurses: 3 (15.8%); District nurses: 3 (15.8%); General practitioners (GPs): 3 (15.8%); Palliative care physicians: 2 (10.5%); Pharmacists: 3 (15.8%); Service leaders and policy stakeholders: 5 (26.3%)	Patients: 3 (27%); Informal (lay) carers: 8 (73%)
Experience in end-of-life care (years)	Mean (SD): 18 (8.4)	Not applicable
Primary diagnosis of patients, n (%)	Not applicable	Advanced cancer: 3 (100%)
Relationship to patient (informal carers only), n (%)	Not applicable	Spouse/partner: 3 (37.5%); Adult child or grandchild: 4 (50%); Friend: 1 (12.5%)

The analytical outcomes are organized according to the seven dimensions of the TFA, with representative extracts integrated to capture the perceived obstacles and enablers within each category. Across all thematic fields, respondents articulated an interplay between facilitators that drive acceptability and distinct barriers, which frequently stem from emotional, moral, or practical concerns arising within the architecture of the TFA.

Affective attitude

This dimension evaluates participants' emotional reactions to the Palliate program. On the whole, respondents demonstrated favorable attitudes toward the program, noting its capacity to empower family caregivers and reduce pressure on clinical staff. One pharmacist stated:

"I believe it is a worthwhile concept, to be honest. Exceptionally practical. It would assist a large number of individuals. It represents a significant move in a positive direction, and I feel it is well overdue." (Case 6, pharmacist).

Informal caregivers demonstrated a readiness to engage with the program, highlighting how valuable it is to allow their relatives to pass away at home with their dignity intact. One caregiver noted:

"Yes. I approved of every aspect of it. Because, as I mentioned, it strikes a very personal chord with me." (Case 15, lay carer, possesses direct experience with Palliate).

Conversely, several healthcare professionals expressed conflicted emotions, drawing attention to the potential psychological distress experienced by laypersons required to deliver end-of-life injections. As one district nurse detailed:

"I am somewhat stuck in the middle. For certain individuals, it is absolutely appropriate; for others, I would harbor reservations. I would need to know them thoroughly and want to witness them performing the task. Yes, I would feel a bit anxious." (Case 10, district nurse).

This category highlighted a mixture of support and emotional hesitation, uncovering a foundational barrier of psychological discomfort that influenced how acceptable the intervention was perceived to be.

Burden

This construct evaluates the perceived exertion required from stakeholders to engage with Palliate. Both family caregivers and healthcare practitioners acknowledged the substantial emotional and functional burden tied to the program. One caregiver described the intensive nature of this caregiving responsibility:

"It drains you physically, mentally, and emotionally, absolutely… simply having to be there… 24 hours a day, day after day… I administered a significant number of injections to her… approximately 70 or 80 injections over that period." (Case 16, lay carer, possesses direct experience with Palliate).

Conversely, some healthcare providers argued that this initial devotion of time and psychological energy could ultimately decrease overall pressure on health services. A GP observed:

"It demanded quite a bit of time initially to ensure the family members felt confident and adequately prepared… however, once everything was fully established, it eliminates several clinical visits." (Case 12, GP, involved in recommending Palliate).

Nonetheless, anxieties regarding psychological overwhelm remained prominent, especially concerning the emotional strains placed on both clinicians and families during complicated decision-making periods. One palliative care physician noted:

"We understate how terrifying that experience can be… are we underestimating the magnitude of the power we are placing in the hands of families?" (Case 19, former national clinical director of a palliative/end-of-life care charity – in reference to medication administration).

Within this domain, burden manifested primarily as emotional strain, perceived role overload, and the psychological weight of duty, emphasizing obstacles related to psychological well-being and workload pressures.

Ethicality

This construct relates to the degree to which Palliate aligns with the personal values or professional principles of the participants. Respondents raised moral questions regarding the relocation of clinical responsibilities onto family members. A pharmacist highlighted the risk of role confusion:

"Are we placing individuals in a problematic scenario by forcing them to act as clinical providers rather than family members? Because of this, medication administration by lay-carers must always remain a completely voluntary and highly willing choice." (Case 6, pharmacist).

Caregivers similarly expressed anxiety regarding the potential of inadvertently causing injury. One patient remarked:

"The anxiety of hurting the patient and the consequences if I cause them harm in any manner. Some individuals might reasonably ask, well, why isn't a qualified medical professional who has been trained for this task carrying it out?" (Case 5, patient).

In contrast, several participants interpreted the Palliate program as a deeply compassionate framework. One caregiver reflected:

"It certainly did not feel like there were any moral or ethical problems from my perspective. You know, I am providing essential care to my dying wife. It strikes me as an incredibly compassionate act to perform." (Case 16, lay carer, possesses direct experience with Palliate).

This domain highlighted ethical friction as a primary barrier, particularly in terms of role conflict, moral hesitation, and perceived disparities in the distribution of responsibility. These concerns were juxtaposed with viewpoints that characterized the practice as an act of compassion in line with personal values.

Perceived effectiveness

This construct examines the degree to which participants believed Palliate would realize its intended goals. A large number of respondents believed that Palliate could markedly enhance symptom management and alleviate unnecessary suffering caused by waiting for professional clinicians to arrive. A district nurse commented:

"I have experienced situations where we arrived at a patient's home late, and they were in extreme pain. If someone else had been present to administer that medication, it would certainly prevent individuals from deteriorating to that severity." (Case 10, district nurse).

In a similar vein, a caregiver underscored the advantages of having immediate access to symptom relief:

[Participant was asked whether they believed the intervention assisted in managing their relative's symptoms]: "An absolute yes… considering the extreme intensity of the pain she endured, how distressing it was, and the crucial importance of remaining at home… there is a very definite yes to that question." (Case 16, lay carer, possesses direct experience with Palliate).

However, multiple participants pointed out that successful outcomes depend heavily on the careful selection of caregivers and the provision of robust support. As one palliative care physician emphasized:

"If you select your patient and their family group meticulously, I believe they will experience a better death… they are far more likely to receive prompt symptom control." (Case 19, former national clinical director of a palliative/end-of-life care charity).

[Participant was asked whether they believed the intervention would enhance the management of patient symptoms at home]: "I believe so without reservation… anything that… proves to be successful and efficient… that can optimize the experience of dying at home can only be a positive development." (Case 20, public health professional).

Obstacles identified within this domain were linked to anxieties regarding inconsistent execution, variations in caregiver competence, and reliance on reliable support infrastructure, which were viewed as essential prerequisites for efficacy.

Intervention coherence

This construct assesses how thoroughly participants comprehended Palliate and its underlying objectives. Most respondents displayed a clear conceptual grasp of the program. A healthcare commissioner observed:

"This initiative is completely self-evident. It can be explained in just two sentences, and its purpose is immediately obvious." (Case 7, ICB commissioner, possesses experience commissioning Palliate in their region).

One patient further clarified the uncomplicated nature of the procedure:

"Injecting medication beneath the skin is relatively straightforward. It is a task already performed in certain community settings by informal caregivers, making it entirely feasible to train an individual because the process itself is quite simple." (Case 11, patient).

Recommendations for refining operational coherence included incorporating pre-measured medication doses and video-guided instructional resources, as highlighted by a public health specialist:

"I believe supplementing the training with video guides is an excellent concept… that would make the process much easier to manage, particularly for older individuals." (Case 20, public health professional).

In this domain, barriers emerged regarding the clarity of information and confidence in the provided training tools. Participants' recommendations for structured, readily accessible resources highlighted an opportunity to optimize comprehension and ensure uniform understanding.

Self-Efficacy

This construct measures participants' confidence in their ability to successfully interact with and execute Palliate. Although multiple respondents believed that family caregivers could acquire the necessary competencies given sufficient instruction, levels of confidence fluctuated. A pharmacist observed rapid skill acquisition in one instance:

"[Discussing a caregiver she instructed]: She grasped the concept within a couple of hours, and was satisfied, at ease, and capable within a couple of hours of instruction." (Case 1, pharmacist, possesses experience utilizing a variation of Palliate).

A patient articulated conditional confidence:

"I believe that, provided they receive the training to perform it, then yes, that is perfectly acceptable. If it is an activity they feel capable of undertaking, then that is positive. However, if they do not, then perhaps not everyone would feel at ease performing it." (Case 2, patient).

Conversely, certain respondents highlighted the apprehension that family caregivers might experience when executing clinical duties:

"I would be concerned about them experiencing fear regarding that task… the volume of individuals who articulate to [me], 'I am not a nurse. I do not understand. I am not a nurse.'" (Case 26, end-of-life care nurse).

This dimension illustrated barriers centered on inconsistent confidence and a dread of clinical obligations, underscoring the need for continuous reassurance, oversight, and instructional reinforcement.

Opportunity costs

This construct concerns what stakeholders might forfeit (e.g., time, assets, alternative pursuits) by participating in Palliate. Family caregivers reflected on the substantial personal concessions demanded. One caregiver detailed their absolute immersion within the caregiving assignment:

"I relinquished everything else and solely attended to [name] … that became my new employment." (Case 13, lay carer, possesses direct experience with Palliate).

Healthcare practitioners recognized these obstacles, particularly for individuals managing competing obligations:

"It is primarily going to be appropriate for caregivers who remain present continuously. Otherwise, it is largely futile instructing an individual who will not be on hand when an emergency arises." (Case 19, former national clinical director of a palliative/end-of-life care charity).

Obstacles within this category were articulated through the significant personal toll on time, psychological stamina, and social isolation, indicating that acceptability depended on the provision of sufficient assistance and flexibility regarding caregiver participation.

General acceptability

Notwithstanding the documented challenges, respondents predominantly regarded Palliate as an acceptable and advantageous framework. One caregiver reflected on its constructive influence:

"It was incredibly precious… I believe it would have resulted in a highly distinct, far poorer experience to have endured what we went through without this resource… I felt exceptionally honored and appreciative to participate in it." (Case 16, lay carer, possesses direct experience with Palliate).

Healthcare practitioners likewise expressed broad support, provided that suitable safety protocols and educational frameworks were established. One palliative care physician noted:

"Yes, I consider them highly acceptable… any initiative to assist patients and families to feel autonomous, stay in their domestic environment, and achieve effective symptom control." (Case 8, palliative care doctor).

Across all seven TFA categories, respondents generally viewed Palliate as acceptable, provided caregivers were assisted through structured training, safety measures, and optional involvement. Obstacles were articulated through psychological discomfort, moral friction, and role strain. They perceived deficiencies in education or assistance, counterbalanced by pronounced perceived advantages such as enhanced immediacy of care, caregiver autonomy, and congruence with person-centered principles. In summary, this integration demonstrates both the recognized utility of the intervention and the environmental criteria dictating its acceptability. The TFA offered an effective analytical framework for uncovering enablers and barriers across distinct domains.

An integrated summary table aligning obstacles and enablers with the TFA categories, along with literal extracts, is available in Additional file 1.

This study investigated the viewpoints of various stakeholders regarding Palliate, a program enabling family caregivers to administer subcutaneous medication to support home-based end-of-life care. These results offer preliminary insights into integrating such models into healthcare frameworks increasingly focused on home-based care. Although the concept of family-administered subcutaneous treatment is well established, formalized, nurse-led strategies such as Palliate remain underrepresented in the academic literature. By capturing perspectives from a comprehensive group of stakeholders—including patients, family carers, clinicians, and policy-makers—this research provides a detailed look at the practical, ethical, and psychological dimensions of involving laypersons in end-of-life medication administration, utilizing both hypothetical and real-world viewpoints.

Our analysis demonstrates that while Palliate is widely regarded as acceptable and potentially advantageous, it introduces a delicate balance of benefits and risks that demand careful management. The data indicate that although respondents across all cohorts identified the strategy's capacity to facilitate rapid symptom control and increase caregiver autonomy, they raised apprehensions about the psychological, ethical, and functional pressures placed on relatives. Caregivers reported feeling honored to assist their family members, yet they also noted the substantial strain that such duties could place on their mental health and daily routines. Healthcare providers mirrored this conflict, recognizing the administrative advantages alongside the moral complexities of shifting clinical tasks to informal caregivers.

Significantly, multiple respondents in this research did not speak from a purely speculative standpoint; some individuals had direct experience administering medication to a relative, while others had already deployed or recommended the Palliative model in practice. These viewpoints anchored the dataset in real-world applications, increasing the ecological validity of the results and illuminating both the functional benefits and emotional trials associated with the program. While combining speculative and experiential narratives enriches the study, it also underscores the divergence in personal experiences, reinforcing the necessity for customizable implementation models.

This delicate balance aligns with historical research demonstrating that strategies meant to empower family caregivers during end-of-life care often generate unintended psychological effects, such as heightened levels of accountability, anxiety, and guilt [48, 49]. Furthermore, these observations correspond with studies showing that while caregivers value active participation, they frequently report feeling inadequately prepared or isolated when clinical duties are assigned to them [50, 51].

Our observations also underscore the critical role of environmental context. This investigation was performed within the UK's National Health Service (NHS), where national strategy progressively encourages care closer to home [52]. In this framework, Palliate offers an opportunity to facilitate the transition toward person-centered, community-focused care by aligning service delivery with patient choices and national goals. For instance, this aligns with the Commission on Palliative and End-of-Life Care's guidance, which emphasizes shifting care from clinical hospital settings to community settings [53]. Conversely, healthcare networks in alternative nations, such as Australia and Canada, may distribute resources for palliative services differently, with certain models providing superior community-based assistance or regionalized programs [54, 55]. Consequently, the viability and acceptability of family-administered strategies may fluctuate across international borders, shaped by unique service structures, statutory parameters, and cultural assumptions regarding family caregiving responsibilities.

Critically, multiple participants expressed anxiety regarding the potential confusion between this program and assisted dying, which is currently set to be legalized in England and Wales [56]. While Palliate is engineered specifically to control distressing symptoms during the dying process—rather than to accelerate mortality—such viewpoints mirror the intense ethical sensitivities surrounding this practice. This boundary must be explicitly communicated to both families and clinicians to prevent misconceptions and ensure the intervention is recognized as a legitimate palliative methodology distinct from assisted dying.

Alongside ethical factors, the logistical considerations of keeping injectable medications, particularly controlled drugs, inside the home environment must be meticulously managed. This involves evaluating the potential risks of improper use, accidental delivery, or unauthorized diversion, alongside the emotional strain experienced by caregivers tasked with monitoring these substances. Unambiguous instructions on secure storage and disposal protocols, along with comprehensive caregiver education, are vital components of any deployment framework to ensure safety and confidence during home implementation.

In addition to these concrete findings, this project advances theoretical conceptions of intervention acceptability within palliative care. Utilizing the TFA proved valuable for organizing the analysis across psychological, operational, and moral dimensions. However, our results indicate that, for emotionally intensive interventions such as Palliate, domains such as burden, ethicality, and opportunity costs are shaped not merely by individual outlooks, but also by interpersonal dynamics and broader systemic contexts. Acceptability was frequently conditional and subject to change, shifting in tandem with caregiver confidence, available support networks, and evolving scenarios. These observations highlight both the usefulness of the TFA for structuring data analysis and its constraints, as its standardized categories may limit the discovery of novel, cross-cutting themes. Future refinements of the TFA could better integrate the interpersonal and environmental nuances characteristic of palliative care programs.

The investigation gathered a wide range of viewpoints from medical professionals and lay stakeholders, though ethnic representation was limited. While the inclusion of multiple clinical disciplines enhances the applicability of the findings, the narrow ethnic profile underscores the need for ongoing research into how cultural values and preferences may alter acceptability across more diverse demographics.

Implications for practice

In line with the TFA concepts of self-efficacy and burden, caregivers must receive training that simultaneously fosters confidence while avoiding excessive strain. Participants in this study highlighted the effectiveness of practical, hands-on tutorials supplemented by written or digital video tools customized to individual learning styles. This training should be periodically refreshed to reinforce core competencies. International data corroborates this methodology—for example, a study conducted in Australia demonstrated that informal caregivers can competently deliver subcutaneous medications when supported by structured, caregiver-focused instruction [29].

The dimension of perceived effectiveness was intimately connected to the availability of continuous professional guidance. Respondents highly valued access to clinical consultations, particularly when symptom management grew complex or when medication choices had to be made. This corresponds with data from an evaluation of out-of-hours palliative telephone services, which showed that rapid access to clinical advice minimized preventable hospitalizations while increasing caregiver confidence and satisfaction [57].

Ethicality similarly emerged as an essential factor. Caregivers reflected deeply on the psychological and moral weight of participating in end-of-life care, especially regarding the administration of injectable therapies. Tackling these worries openly and directly is imperative.

Finally, the TFA domain of opportunity costs underscores the need to ensure that caregiver engagement remains entirely voluntary. Medical practitioners should evaluate each caregiver's capacity, willingness, and broader personal obligations before incorporating them into the program. Alternate care structures must be provided whenever participation is unfeasible or unwanted.

By anchoring implementation strategies in the TFA and incorporating international evidence, healthcare operations can establish safe, standardized practices—including tailored educational tracks, accessible clinical support, and adaptable pathways—while remaining attentive to caregivers' psychological, moral, and functional needs across diverse cultural and legal environments.

Limitations

This project was an exploratory qualitative study designed to formulate insights rather than produce generalizable conclusions. Consequently, uncertainty was native to the interpretive character of the analysis, and the insights should be interpreted as context-specific. While the research incorporated various professional and lay viewpoints, the sample was geographically restricted to the UK, and the majority of participants identified as White British. These parameters limit the transferability of the results to alternative cultural frameworks or healthcare systems, particularly when caregiving traditions or ethical standards diverge.

Furthermore, although the study benefited from including individuals with direct experience administering or monitoring the intervention, these insights were not consistent across the dataset. Certain respondents spoke entirely from a hypothetical perspective. This combination of experiential and speculative narratives offers depth but introduces variance regarding familiarity and emotional proximity to the intervention. Voluntary response bias may also have shaped the outcomes, as individuals with stronger convictions or experiences were potentially more inclined to participate.

Reflexivity was integrated throughout the research workflow, featuring continuous debates among the multidisciplinary team to detect and mitigate interpretive bias during data gathering and analysis. Nevertheless, the investigators' professional backgrounds in palliative and end-of-life care may have colored the interpretation of the data.

Lastly, utilizing a deductive framework analysis structured by the TFA offered conceptual organization but may have restricted the development of novel or intersecting themes. Future investigations should examine alternative or complementary analytical strategies and assess broader, real-world deployments to evaluate the wider relevance of these insights.

Opportunities for future work

Palliate serves as an example of a complex intervention, involving numerous elements that likely influence successful implementation and execution. The efficacy of Palliate regarding outcomes central to patients must be examined through mixed-methods, multi-center trials that account for the impact of social determinants of health on clinical outcomes and service access. A deeper understanding of the factors that determine safe and successful implementation, paired with comprehensive health economic evaluations, will help shape equitable service delivery and business case designs. Finally, researching the integration of digital tools (such as telehealth consultations, electronic medication records, and clinical decision-support software) presents an avenue to maximize professional oversight while protecting the autonomy and rapid responsiveness that family caregivers value.

Conclusion

This investigation demonstrated that Palliate is broadly acceptable to a varied sample of UK-based stakeholders, including patients, family carers, and medical professionals. Respondents underscored prospective benefits, including enhanced symptom control, accelerated access to medication, and greater independence for caregivers. Nonetheless, they concurrently identified meaningful emotional and moral considerations, particularly regarding perceived accountability, clinical oversight, and the imperative to differentiate the program explicitly from assisted dying.

Crucially, the data indicate that acceptability is not a fixed attribute but a conditional state—modulated by interpersonal dynamics, psychological readiness, and institutional support mechanisms. This research provides fresh insights into the relational and environmental variables that influence intervention acceptability, expanding the utility of the TFA within end-of-life care frameworks.

Future deployment must be supported by transparent training protocols, continuous professional development, and a voluntary participation framework that honors caregivers' preferences and personal thresholds. Additional research is needed to evaluate the safety, efficacy, and feasibility of the intervention across diverse cultural settings and health care systems, ensuring that informal caregivers are supported rather than overwhelmed.

Acknowledgments: The authors gratefully acknowledge the contributions of patients, professionals, and other members of the public who participated in the interviews and generously shared their perspectives. We also thank Lynn McGowan for generously sharing her expertise and insights.

Conflict of interest: None

Financial support: This research was funded by the Oak Foundation (Grant Number: OFIL-20-279). Infrastructure support for this study was provided by the National Institute for Health and Care Research (NIHR) North West London Patient Safety Research Collaboration (PSRC). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Ethics statement: This study received a favourable ethical opinion from the West of Scotland Research Ethics Committee 4, part of the UK Health Department's Research Ethics Service (REC reference 24/WS/0026), for conduct in the NHS and private healthcare settings. The study also received regulatory approvals from the Health Research Authority (HRA) for sites in England, and from Health and Care Research Wales (HCRW) for sites in Wales. Informed consent was obtained from all study participants before any data collection. The research was conducted in accordance with the principles of the Declaration of Helsinki.

References

1. Sleeman KE, Timms A, Gillam J, Anderson JE, Harding R, Sampson EL, et al. Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a National documentary analysis. BMC Palliat Care. 2021;20:1–10. doi:10.1186/S12904-021-00802-6/TABLES/1
2. Department of Health & Social Care. The Government's revised mandate to NHS England for 2018-19 2019. https://assets.publishing.service.gov.uk/media/5ce3cf9840f0b627e6e7b194/revised-mandate-to-nhs-england-2018-to-2019.pdf (accessed May 6, 2025).
3. Pollock K, Caswell G, Turner N, Wilson E. The ideal and the real: patient and bereaved family caregiver perspectives on the significance of place of death. Death Stud. 2024;48:312–25. doi:10.1080/07481187.2023.2225042
4. Shepperd S, Gonçalves-Bradley DC, Straus SE, Wee B. Hospital at home: home-based end-of-life care. Cochrane Database Syst Rev. 2021;3. doi:10.1002/14651858.CD009231.PUB3
5. Nysæter TM, Olsson C, Sandsdalen T, Wilde-Larsson B, Hov R, Larsson M. Preferences for home care to enable home death among adult patients with cancer in late palliative phase – a grounded theory study. BMC Palliat Care. 2022;21:1–10. doi:10.1186/S12904-022-00939-Y/FIGURES/1
6. NHS England. NHS plan to cut avoidable admissions to further boost efforts to reduce waiting times 2024. https://www.england.nhs.uk/2024/05/nhs-plan-to-cut-avoidable-admissions-to-further-boost-efforts-to-reduce-waiting-times/ (accessed May 12, 2025).
7. Gott M, Gardiner C, Ingleton C, Cobb M, Noble B, Bennett MI, et al. What is the extent of potentially avoidable admissions amongst hospital inpatients with palliative care needs? BMC Palliat Care. 2013;12:9. doi:10.1186/1472-684X-12-9
8. Hoare S, Kelly MP, Barclay S. Home care and end-of-life hospital admissions: a retrospective interview study in English primary and secondary care. Br J Gen Pract. 2019;69:e561–9. doi:10.3399/BJGP19X704561
9. Pinto S, Lopes S, de Sousa AB, Delalibera M, Gomes B. Patient and family preferences about place of End-of-Life care and death: an umbrella review. J Pain Symptom Manage. 2024;67:e439–52. doi:10.1016/J.JPAINSYMMAN.2024.01.014
10. Costa V, Earle CC, Esplen MJ, Fowler R, Goldman R, Grossman D, et al. The determinants of home and nursing home death: a systematic review and meta-analysis. BMC Palliat Care. 2016. doi:10.1186/S12904-016-0077-8
11. Johnston EE, Martinez I, Currie E, Brock KE, Wolfe J. Hospital or home? Where should children die and how do we make that a reality? J Pain Symptom Manage. 2020;60:106–15. doi:10.1016/J.JPAINSYMMAN.2019.12.370
12. Macmillan Cancer Support. The Final Injustice: Variation in end of life care in England. 2017. https://www.macmillan.org.uk/_images/MAC16904-end-of-life-policy-report_tcm9-321025.pdf. (accessed November, 11, 2025).
13. Davidson S, Gentry T. Age UK End of Life Evidence Review. 2013. https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb_oct13_age_uk_end_of_life_evidence_review.pdf. (accessed November 11, 2025).
14. Nuffield Trust. Public expenditure in the last year of life n.d. https://www.nuffieldtrust.org.uk/research/public-expenditure-in-the-last-year-of-life (accessed July 20, 2025).
15. Kestenbaum MG, Vilches AO, Messersmith S, Connor SR, Fine PG, Murphy B, et al. Alternative routes to oral opioid administration in palliative care: a review and clinical summary. Pain Med. 2014;15:1129–53. doi:10.1111/PME.12464
16. Masman AD, van Dijk M, Tibboel D, Baar FPM, Mathôt RAA. Medication use during end-of-life care in a palliative care centre. Int J Clin Pharm. 2015;37:767. doi:10.1007/S11096-015-0094-3

17. Poolman M, Roberts J, Wright S, Hendry A, Goulden N, Holmes EAF, et al. Carer administration of as-needed subcutaneous medication for breakthrough symptoms in people dying at home: the CARiAD feasibility RCT. Health Technol Assess. 2020;24:1. doi:10.3310/HTA24250
18. First Community Health & Care. Administering injectable medication n.d. https://www.firstcommunityhealthcare.co.uk/administering-injectable-medication-information-for-patients-families-and-friends/ (accessed July 22, 2025).
19. Hodge G, Kallis G, Oh TM, Wheat H, Pearce S. Exploring perceived barriers to palliative and end of life care provision in South-West England: bringing together the perspectives of professionals, patients, and families. Front Sociol. 2024;9:1488688. doi:10.3389/FSOC.2024.1488688/BIBTEX
20. Cerni J, Hosseinzadeh H, Mullan J, Westley-Wise V, Chantrill L, Barclay G, et al. Does geography play a role in the receipt of end-of-life care for advanced cancer patients? Evidence from an Australian local health district population-based study. J Palliat Med. 2023;26:1453. doi:10.1089/JPM.2022.0555
21. Anwar A, Amin MK, Anwar S, Shahzad M. Bridge the gap: addressing rural End-of-Life care disparities and access to hospice services. J Pain Symptom Manage. 2024;68:e280–6. doi:10.1016/J.JPAINSYMMAN.2024.07.001
22. Wilson E, Morbey H, Brown J, Payne S, Seale C, Seymour J. Administering anticipatory medications in end-of-life care: a qualitative study of nursing practice in the community and in nursing homes. Palliat Med. 2015;29:60. doi:10.1177/0269216314543042
23. Bainbridge D, Brazil K, Krueger P, Ploeg J, Taniguchi A. A proposed systems approach to the evaluation of integrated palliative care. BMC Palliat Care. 2010;9:8. doi:10.1186/1472-684X-9-8
24. Poolman M, Roberts J, Wright S, Hendry A, Goulden N, Holmes EAF, et al. Carer administration of as-needed subcutaneous medication for breakthrough symptoms in people dying at home: the CARiAD feasibility RCT. Health Technol Assess. 2020;24:1–149. doi:10.3310/HTA24250
25. O'Hara L, Evans CJ, Bowers B. Family carers' administration of injectable medications at the end of life: a service evaluation of a novel intervention. Br J Community Nurs. 2023;28:284–92. doi:10.12968/BJCN.2023.28.6.284
26. Anderson BA, Kralik D. Palliative care at home: carers and medication management. Palliat Support Care. 2008;6:349–56. doi:10.1017/S1478951508000552
27. Poolman M, Shuler A. Accessed May 12. In the context of the national (Welsh) COVID-19 response POLICY AND PROCEDURE 2020. https://wales.pallcare.info/index.php?p=sections&sid=11 (2025).
28. Short C, Scott A. PA7 developing a culture of medication safety in the palliative care home setting - supporting choices in place of care and death. BMJ Support Palliat Care. 2015;5(Suppl 1). doi:10.1136/BMJSPCARE-2015-000906.67.:A21.3-A21
29. Healy S, Israel F, Charles M, Reymond L. Laycarers can confidently prepare and administer subcutaneous injections for palliative care patients at home: a randomized controlled trial. Palliat Med. 2018;32:1208. doi:10.1177/0269216318773878
30. Pitts JA, Geller G, Muller A. Caregiver experiences in administering subcutaneous medications to community palliative care patients: integrative review. Home Health Care Serv Q. 2023;42:154–72. doi:10.1080/01621424.2022.2164539
31. Antunes B, Bowers B, Winterburn I, Kelly MP, Brodrick R, Pollock K, et al. Anticipatory prescribing in community end-of-life care in the UK and Ireland during the COVID-19 pandemic: online survey. BMJ Support Palliat Care. 2020;10:343–9. doi:10.1136/BMJSPCARE-2020-002394
32. Lee L, Howard K, Wilkinson L, Kern C, Hall S. Developing a policy to empower informal carers to administer subcutaneous medication in community palliative care; a feasibility project. Int J Palliat Nurs. 2016;22:369–78. doi:10.12968/IJPN.2016.22.8.369
33. Robinson K, Mackie J, Keir NHS, Lothian S, Lewis M, Heneghan J, Burdon J. 107 A service evaluation of a new policy to support carers giving subcutaneous anticipatory medications at home at end of life within Southern Derbyshire, population of 607,000. BMJ Support Palliat Care. 2021;11:A47–47. doi:10.1136/SPCARE-2021-PCC.125
34. NHS. Policy for Patient or Carer Administration of Subcutaneous Medication (Palliative Care). 2023. https://northyorkshireccg.nhs.uk/wp-content/uploads/2021/03/HDFT-policy-for-patient-or-carer-adminstration-of-subcutaneous-medication-pa._.pdf (accessed May 12, 2025).
35. NHS. Dorset Shared Care Protocol for informal carer administration of subcutaneous mediations for pain and symptom management in Community Palliative care 2020. https://nhsdorset.nhs.uk/Downloads/aboutus/medicines-management/Other%20Guidelines/Protocol%20for%20carer%20sc%20admin%20-%20Apr%202020.pdf?boxtype=pdf&g=false&s=true&s2=false&r=wide (accessed May 12, 2025).
36. Poolman M, Roberts J, Byrne A, Perkins P, Hoare Z, Nelson A, et al. CARer-Administration of as-needed subcutaneous medication for breakthrough symptoms in homebased dying patients (CARiAD): study

protocol for a UK-based open randomised pilot trial. Trials. 2019;20:1–16. doi:10.1186/S13063-019-3179-9/TABLES/2
37. NIHR JLA. Palliative and end of life care n.d. https://www.jla.nihr.ac.uk/priority-setting-partnerships/palliative-and-end-of-life-care (accessed July 20, 2025).
38. Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. BMC Health Serv Res. 2017;17:1–13. doi:10.1186/S12913-017-2031-8
39. Sekhon M, Cartwright M, Francis JJ. Development of a theory-informed questionnaire to assess the acceptability of healthcare interventions. BMC Health Serv Res. 2022;22:1–12. doi:10.1186/S12913-022-07577-3/TABLES/2
40. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007. doi:10.1093/intqhc/mzm042
41. NHS. What end of life care involves - NHS. 2022. https://www.nhs.uk/tests-and-treatments/end-of-life-care/what-it-involves-and-when-it-starts/ (accessed August 8, 2025).
42. Guest G, Bunce A, Johnson L. How many interviews are enough? Field Methods. 2006;18:59–82. doi:10.1177/1525822X05279903
43. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77–101. doi:10.1191/1478088706qp063oa
44. Qualtrics. Qualtrics XM. Qualtrics. 2023. https://www.qualtrics.com.
45. Lumivero. NVivo. 2024. https://www.lumivero.com..
46. Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. Int J Qual Methods. 2017. doi:10.1177/1609406917733847
47. Johnson JL, Adkins D, Chauvin S. A review of the quality indicators of rigor in qualitative research. Am J Pharm Educ. 2020;84:7120. doi:10.5688/AJPE7120
48. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. J Clin Nurs. 2009;18:1379–93. doi:10.1111/J.1365-2702.2008.02405.X
49. Hudson P, Trauer T, Kelly B, O'Connor M, Thomas K, Zordan R, et al. Reducing the psychological distress of family caregivers of home based palliative care patients: longer term effects from a randomised controlled trial. Psychooncology. 2014;24:19. doi:10.1002/PON.3610
50. Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database Syst Reviews. 2011. doi:10.1002/14651858.CD007617.PUB2/MEDIA/CDSR/CD007617/IMAGE_N/NCD007617-CMP-001-03.PNG
51. Parand A, Garfield S, Vincent C, Franklin BD. Carers' medication administration errors in the domiciliary setting: a systematic review. PLoS One. 2016. doi:10.1371/JOURNAL.PONE.0167204
52. NHS England. Ambitions for Palliative and End of Life Care: A national framework for local action 2021–2026 2022. https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/. (accessed May 12, 2025).
53. Finlay I, Richards M, Maskell R, Abrahams C, Brown M, Campbell et al. Palliative Care and End-of-Life Care: Opportunities for England (Volume 1), The Commission on Palliative and End-of-Life Care. 2025. https://img1.wsimg.com/blobby/go/e5bbd9ef-01fd-45c0-b4f4-1cf6b62157b9/VOLUME%201%20REPORT%20FINAL%20170625.pdf. (accessed May 12, 2025).
54. Australian Government Department of Health and Aged Care. The National Palliative Care Strategy. 2018;2018. https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018?language=en. (accessed May 12, 2025).
55. Canadian Partnership Against Cancer & Health Canada. The Canadian interdisciplinary palliative care competency framework A curriculum guide for educators and reference manual for disciplines providing palliative care. Toronto: 2021. https://s22457.pcdn.co/wp-content/uploads/2021/07/palliative-care-competency-framework-EN.pdf. (accessed May 12, 2025).
56. The Guardian. Assisted dying set to become law in England and Wales after MPs pass bill 2025. https://www.theguardian.com/society/2025/jun/20/assisted-dying-law-england-and-wales-bill-passed (accessed June 21, 2025).
57. Worth A, Boyd K, Kendall M, Heaney D, Macleod U, Cormie P, et al. Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals. Br J Gen Pract. 2006;56:6.