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Identifying the Transition to the Palliative Phase in Patients with COPD and Heart Failure in Primary Care: A Mixed-Methods Study

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Abstract

Locating the precise window when patients suffering from chronic obstructive pulmonary disease (COPD) or heart failure (HF) enter the palliative stage remains a persistent clinical obstacle. Detecting this transition early is vital for mapping patient requirements and launching holistic supportive care, yet such recognition often comes too late. Because the majority of individuals diagnosed with HF and COPD remain at home for most of their illness, identifying these shifts within community care networks is vital for predicting needs and preserving patient well-being. On a global scale, only 14% of those who require end-of-life care actually receive it. Primary care settings infrequently deploy formal screening instruments, leaving identification almost entirely to individual clinical judgment. Machine learning (ML) offers a viable approach to uncovering hidden patterns in routine medical records, enabling earlier, more standardized detection of supportive care needs. Consequently, this investigation sought to establish and rank the clinical indicators and symptoms that reflect a shift into the palliative phase for individuals with COPD or HF. These insights are intended to guide the engineering of an ML infrastructure that helps community-based nurses promptly identify palliative care needs. Operating within a pair of community care agencies, this mixed-methods project was executed across four distinct stages: (1) qualitative interviews utilizing a semi-structured format with nine community nursing practitioners; (2) an accelerated literature evaluation of 13 publications addressing palliative indicators in HF and COPD populations; (3) two multidisciplinary focus group sessions featuring 18 experts; and (4) an assessment survey distributed to 115 community nursing staff members to validate and rank the identified indicators. The qualitative findings were analyzed using thematic analysis, whereas descriptive statistics were used to evaluate survey outcomes. Clinical decline emerged as a multi-faceted phenomenon spanning physical, psychological, social, and spiritual realms, unfolding alongside escalating healthcare demands. Physical decline was characterized by aggravating symptoms and diminishing functional independence. In contrast, the psychological and social spheres were marked by anxiety, isolation, and an increasing reliance on others, which was frequently brought to light by family caregivers. The spiritual realm was marked by existential suffering and a fading sense of purpose. Heightened care requirements were evidenced by greater healthcare utilization, unscheduled medical interventions, and emergency hospitalizations. The data from all research steps were synthesized to rank the core indicators most relevant to daily community nursing practice. This research mapped and prioritized the specific clinical indicators used by community-based nursing staff to detect the palliative stage in individuals living with HF and COPD. These data establish a practice-grounded framework for engineering an operational ML tool designed to optimize the early detection of palliative needs and facilitate holistic community-based care.

Keywords: Advanced care planning, COPD, Heart failure, Palliative care, Primary care nursing, Machine learning

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Introduction

Pinpointing the exact timeframe when individuals with chronic conditions—such as chronic obstructive pulmonary disease (COPD) and heart failure (HF)—cross over into the palliative phase remains a complex puzzle in day-to-day clinical practice [1, 2]. This is an exceptionally difficult task in the context of COPD and HF due to their protracted, unpredictable trajectories, where patient decline happens gradually over time rather than manifesting as a sharp, unambiguous medical crisis. Palliative medicine offers comprehensive assistance for individuals confronting terminal diagnoses or approaching the end of life, while concurrently supporting their immediate families [3]. The core objective is to ensure the prompt detection of supportive care requirements and the initiation of a holistic palliative strategy. This strategy encompasses advance care planning (ACP). This structured dialogue helps patients clarify and articulate their personal values, preferences, and goals regarding future medical treatment, including choices about life-sustaining interventions and the designation of a proxy decision-maker [4-7]. Even so, this clinical pivot point is often overlooked until it is too late, leading to missed opportunities to implement proactive, patient-aligned care plans [8-13].

On a global scale, the demand for palliative services is escalating, driven by an aging demographic and the widening impact of chronic medical conditions [8]. Despite this need, the World Health Organization estimates that only 14% of individuals who require palliative interventions actually receive them [3]. COPD and HF, which impact roughly 300 million and 64 million individuals worldwide, respectively, introduce multi-faceted care demands and highly erratic illness pathways [9-12]. Because the vast majority of these patients reside at home for the bulk of their illness trajectory, general practitioners and district nurses play a pivotal role in identifying these needs early and delivering coordinated palliative services within community settings [13].

The progression of both HF and COPD is fundamentally non-linear, featuring prolonged periods of stability that are abruptly interrupted by acute flare-ups [11, 14]. This non-linear pattern impedes timely detection of evolving palliative care needs. While specific tools exist to uncover these needs, they are generally too broad, lack sufficient validation within chronic organ failure cohorts, and are poorly integrated into everyday community nursing routines [15-20]. As a result, recognizing the palliative phase often relies on subjective judgment by individual practitioners, leading to widespread inconsistency and delayed implementation of comprehensive supportive care, including ACP [21].

While a vast body of medical literature describes the symptoms, treatment protocols, and survival rates associated with end-stage COPD and HF, the majority of these studies focus heavily on terminal illness stages and acute hospital outcomes [22, 23]. Far less academic attention has been paid to how early indicators of clinical decline are identified and decoded within routine daily workflows, particularly in community nursing contexts where patients manage their illnesses at home over prolonged periods. Within this setting, identifying a patient's decline is typically a slow, cumulative process that occurs incrementally; it hinges on the gradual aggregation of subtle changes, clinical intuition, and localized knowledge rather than on isolated, dramatic medical emergencies [24].

To overcome these barriers, there is growing interest in technological aids, particularly machine learning (ML), as a means for healthcare providers to decipher intricate patterns of decline in chronic illnesses. ML has been proposed as a promising method for clinicians to detect complex patterns of clinical deterioration, particularly when the underlying changes occur slowly and stem from multiple overlapping factors [25]. In primary home care, embedding ML-powered diagnostic tools directly into electronic nursing documentation—including unstructured text notes—could help community nurses capture early warning signs of the palliative transition. This is achieved by systematically analyzing trends in patient symptom tracking, prescription drug use, and functional decline [25-27]. Crucially, these digital assets are meant to enhance rather than substitute professional clinical judgment, helping nurses deliver prompt, highly tailored care [28, 29]. It is vital to note that this project does not deploy ML algorithms; instead, it aims to establish a clinically grounded baseline of knowledge regarding signs and symptoms, which is mandatory for the future engineering of ML-driven systems aligned with actual nursing workflows.

This study presents insights gathered directly from community nurses regarding the signs and symptoms linked to the palliative transition for home-dwelling patients with COPD and HF. These data provide a practice-based foundation for improving the early detection of supportive care needs in home environments and can inform the design of future decision-support systems, including ML-integrated models, to foster prompt and holistic palliative care delivery.

Identifying and prioritizing the specific signs and symptoms in patients with COPD and HF that signal a transition toward the palliative phase establishes the groundwork for an ML model. This model is intended to assist primary home-care nurses in the timely detection of palliative care needs and to facilitate the implementation of comprehensive palliative care, including ACP.

Materials and Methods

This mixed-methods study was executed between November 2022 and April 2024. The research took place within two home healthcare agencies delivering community nursing services across urban and semi-urban districts in the Netherlands. These agencies offer a comprehensive suite of home nursing services, primarily targeting older populations and other community-dwelling individuals experiencing intricate care requirements, such as functional impairments, frailty, and progressive or chronic illnesses. Within the healthcare infrastructure of the Netherlands, home nursing services are delivered by a range of practitioners, including licensed registered nurses, vocationally educated nurses, and certified nursing assistants [30]. Throughout this paper, these cohorts are collectively designated as home-based nursing professionals.

The investigation used an exploratory, sequential, mixed-methods design. The insights gathered from each distinct phase informed the execution of the subsequent stage: qualitative data from interviews and the rapid literature review guided the formulation of the focus group protocol, while aggregated insights from interviews, focus groups, and the literature review guided the design of the survey instrument. Data integration occurred through an iterative process across all stages, using constant comparison and data triangulation, which enabled continuous refinement of the tracked signs and symptoms. The project was structured into four core elements: (1) semi-structured interviews, (2) a rapid literature review, (3) multidisciplinary focus groups, and (4) a quantitative survey.

Semi-structured interviews

The goal of this phase was to investigate how certified nursing assistants (CNAs) and vocational nurses conceptualize and identify the palliative phase during daily care routines, and to document the specific signs and symptoms associated with this transition. A practice-oriented qualitative methodology was applied [31].

Population

Individuals were eligible if they were Dutch-speaking CNAs or vocational nurses employed by one of the participating home-care institutions in the Netherlands and had at least 2 years of clinical experience managing individuals with COPD or HF. In alignment with the research's core objective, particular emphasis was placed on recruiting certified nursing assistants, given their primary role in day-to-day care provision and their position as initial observers of changes in patient clinical status. Their unique insights were vital for understanding how clinical indicators and palliative-stage symptoms are identified, articulated, and documented within routine workflows.

Student nurses undergoing training who lacked direct patient contact were excluded.

Prospective participants were briefed on the project by an internal liaison within the participating institution. Staff members who showed interest provided their names and email addresses to this liaison, who subsequently passed these details to the research staff to facilitate further communication.

A targeted, purposive sampling method was used to recruit practitioners from a variety of community care teams, thereby ensuring diverse clinical experience with COPD and HF cohorts. Given the relative uniformity of the target group and methodological recommendations for qualitative investigations, a baseline sample size of roughly 10–12 individuals was deemed sufficient to achieve adequate statistical power [32].

Data collection

Eleven individuals (comprising certified nursing assistants and one vocational nurse) were enrolled. The individual interviews spanned 45–60 minutes and occurred at locations selected by the participants in quiet environments free from external disruptions.

Leveraging a semi-structured interview protocol, trained research assistants administered the interviews under the direct oversight of a senior academic investigator (BvG). This senior investigator did not attend the live interviews but managed the preparatory workflows, training sessions, and post-interview debriefings. The interview protocol was engineered using current literature and critically reviewed by two academic researchers (BvG and ES) to maintain methodological rigor and guarantee alignment with the research objective. It centered on two primary thematic areas: (1) overarching perspectives regarding the palliative stage, and (2) the identification and documentation of clinical indicators and symptoms signaling the palliative phase.

All interview sessions were conducted in Dutch, audio-recorded, transcribed word-for-word, stripped of identifying details, and returned to the participants for member checking. This transcription review process was executed to maximize the overall credibility of the research observations. Signed informed consent documentation was gathered from each individual before their enrollment.

Analysis

The workflows for data collection and analysis were conducted iteratively until no novel conceptual themes or observations were identified. The compiled transcripts underwent inductive thematic analysis [33]. The formal coding process was executed independently using Microsoft Excel (2023) by an academic researcher (ES) and

two research assistants, with subsequent reconciliation meetings utilized to iron out any coding variations. The emergent themes provided the baseline conceptual map of palliative-stage signs and symptoms.

Rapid literature review

The core goal was to aggregate and synthesize published data regarding the clinical indicators and symptoms linked to the palliative stage for home-dwelling individuals with COPD and HF within primary care settings. An expedited rapid review method was selected to efficiently aggregate current evidence, following relevant PRISMA guidelines where practical, while remaining synchronized with the exploratory and integrative goals of the overarching mixed-methods framework [34].

Search strategy and study selection

Working in tandem with a professional medical librarian, a comprehensive search protocol was engineered using MeSH descriptors and key phrases spanning three core thematic areas: population (individuals diagnosed with COPD or HF), concept (clinical indicators and symptoms, palliative management, hospice and palliative care nursing, palliative medicine), and context (community-based health systems, nursing care, nursing services). Systematic queries were executed in Epistemonikos, including PubMed. Academic works were selected if they detailed clinical or contextual indicators and symptoms tied to the palliative stage in adult cohorts with COPD or HF. The inclusion criteria were limited to peer-reviewed English-language articles published between 2013 and 2023 and to systematic reviews. A single investigator (GvdB) evaluated all retrieved titles and abstracts, which were subsequently cross-verified by a second academic reviewer (ES). Altogether, 18 citations were evaluated during the title and abstract screening phase, of which 13 were retrieved for complete full-text analysis. Any analytical variations were settled through collaborative consensus dialogues.

Analysis

Data regarding clinical signs and symptoms were compiled using a standardized documentation template designed to capture research methodologies, patient demographics, and documented signs and symptoms. Reflecting the exploratory intent of this literature review, the analysis prioritized mapping reported signs and symptoms rather than conducting a critical appraisal of study quality or calculating primary study replication across the selected review articles. The compiled information was aggregated using a narrative synthesis due to the substantial variations in study methodologies and reported clinical endpoints.

Focus group interviews

The purpose of the focus group sessions was to cross-examine and expand upon the insights generated from both the individual interviews and the rapid literature evaluation. This was accomplished via a collaborative, co-constructive framework involving community nursing professionals alongside other primary healthcare clinicians. This interactive methodology enabled shared synthesis and structural refinement of the data to maximize its clinical utility and alignment with routine workflows, aligning with the foundational tenets of research co-design in health systems research [35].

Population

Participants were selected and approached through a dedicated internal liaison at each of the two participating community care institutions. To be eligible for inclusion, individuals had to meet the following criteria: (1) direct professional involvement in managing individuals with COPD or HF; (2) baseline familiarity with the palliative phase and supportive care frameworks; and (3) the capacity to critically analyze and deliberate on personal clinical experiences. To secure an expansive, comprehensive multidisciplinary viewpoint, practitioners from a wide range of clinical backgrounds were integrated.

Practitioners currently in training, staff members lacking permanent employment contracts, and individuals without direct day-to-day involvement in caring for patients with COPD or HF were excluded from participation. Targeted recruitment drives were conducted via email, internal corporate bulletins, and the participating institutions' digital intranets. Furthermore, internal liaisons systematically flagged and approached specific clinicians who met the predetermined eligibility mandates, subsequently forwarding their professional contact information to the research staff. The eligible pool of participants comprised registered nurses, certified nursing assistants, general practitioners, institutional elderly care physicians, physical therapists, and clinical psychologists with documented experience in managing COPD or HF cohorts alongside involvement in palliative care delivery. The total volume and structural scale of the focus groups were determined by the study's exploratory goals and the intent to generate dynamic, information-rich dialogues rather than to achieve data saturation across all professional disciplines.

Data collection

Two multidisciplinary focus group sessions were conducted, each held at a participating care institution. Each group represented a diverse cross-section of clinical backgrounds, incorporating community nursing staff, general practitioners, specialized elderly care physicians, physical therapists, and clinical psychologists. The group volumes fluctuated between 7 and 11 attendees, a balance that supported both wide-ranging clinical viewpoints and highly interactive, granular debate. These focus group sessions were conducted on-site within the participating institutions, lasted roughly 90 minutes, and used a semi-structured format to maintain analytical uniformity while encouraging uninhibited dialogue.

The group discussion guide was engineered using the cumulative data from the rapid literature evaluation and the individual interviews, focusing on three core areas: (1) the participants' baseline conceptualization of palliative management and the specific transition point into the palliative phase for individuals with COPD and HF; (2) the identification and analysis of physical, psychological, social, and spiritual indicators pointing to this transition; and (3) the mechanisms through which these signs and symptoms are spotted, logged into medical records, and conveyed during daily clinical practice.

To stimulate professional dialogue and encourage collective interpretation, structured interactive activities were integrated, starting with an independent brainstorming task that transitioned into a group debate and, subsequently, clustering of the noted indicators based on their perceived clinical relevance and tracking frequency. Each session was guided by a senior academic moderator (GvdB) and supported by an academic observer (ES), with research assistants recording detailed field observations. The session moderators maintained no previous professional relationships with any of the session participants.

All focus group sessions were conducted in Dutch, audio-recorded, and transcribed word-for-word. Written informed consent forms were obtained from all attendees before the launch of the sessions.

Analysis

Thematic evaluation of the focus group transcripts was guided by a deductive coding taxonomy based on the four overarching dimensions of palliative care identified during the rapid literature assessment. The initial coding process was conducted independently within Microsoft Excel (2023) by a primary researcher (GvdB) alongside a team of research assistants, followed by collaborative meetings to resolve indexing variations. To confirm, update, and rank the previously documented indicators, the focus group observations were systematically cross-referenced with data from the individual interviews [36]. This structural approach allowed the research team to consolidate the signs and symptoms into primary domains while blending multi-professional insights with established empirical literature.

Survey

The survey phase was designed to confirm and rank the clinical indicators and symptoms identified in prior stages of the study by collecting data from a larger pool of nursing practitioners employed at the two participating community healthcare agencies.

Population

Registered nurses, vocational nurses, and CNAs from the pair of participating home-care institutions were invited to enroll in the study. Because of statutory privacy mandates (General Data Protection Regulation), the questionnaire was distributed indirectly through internal corporate contacts at each agency, making the total denominator of reached staff members impossible to calculate. To be included, respondents had to be Dutch-speaking nurses or CNAs with at least two years of professional experience managing individuals with COPD or HF. Healthcare staff in training and individuals lacking direct clinical interaction with patients were excluded from the sample. Enrollment was entirely optional. Given that the project focused on validating and prioritizing indicators identified in earlier phases and that an exact sampling frame was not available due to third-party distribution, no formal sample size calculation was conducted beforehand.

Data collection

The digital questionnaire was administered via the Qualtrics XM platform and comprised 17 custom items designed specifically for this investigation. The baseline survey instrument was originally drafted by a senior researcher (GvdB) using data from the rapid review and personal interviews. This draft was subsequently evaluated by the broader research team (BvG, MPK, and ES), pilot-tested in real-world scenarios by research assistants, and reviewed with designated agency representatives from both institutions to evaluate clarity, clinical utility, and administrative feasibility. Minor structural modifications were executed based on this feedback.

The questionnaire included items prompting staff to specify which clinical signs and symptoms they considered highly relevant or less relevant for detecting the palliative stage, and to rank the specific indicators they believed most strongly pointed to this clinical shift. Open-ended items allowed respondents to submit alternative signs or symptoms they deemed important.

Electronic informed consent was required at the initiation of the questionnaire. Respondents were briefed on the voluntary nature of their participation, the encryption and confidentiality of their data, and their absolute right to exit the interface at any time.

Analysis

Quantitative survey data were analyzed using descriptive statistics (frequencies, mean scores, and standard deviations) in SPSS (version 28). Textual data from the open-ended questions were coded using the four primary palliative care dimensions identified in the literature review, with an additional independent category ("intensification of care") added to capture trends observed during the focus group phase. This statistical approach enabled the research team to validate and rank palliative-stage indicators within an expanded cohort of nursing professionals, yielding an organized taxonomy of signs and symptoms across the four palliative care domains.

Integration of findings

The synthesis of research findings was conducted iteratively throughout the study using a constant-comparison framework. Observations from the individual interviews and the rapid literature review were systematically cross-analyzed to dictate the thematic content and scope of the focus group sessions. Throughout the study, the multidisciplinary research team reviewed interim data repeatedly to assess the clinical relevance of emerging indicators to daily practice. Reflecting the project's exploratory nature, the synthesis framework was intentionally inclusive, aiming to map a comprehensive array of potential palliative indicators rather than dismissing clinical warning signs too early. During the focus group sessions, preliminary data were validated, adjusted, or expanded through multidisciplinary debate. Any variations in interpretation were discussed by the research team until a complete consensus was achieved. The quantitative survey was then deployed to definitively confirm and rank the integrated taxonomy of signs and symptoms.

Ethical considerations

The research process conformed to the ethical guidelines of the Declaration of Helsinki and the Personal Data Protection Act [37, 38]. The study protocol was reviewed and granted formal approval by the Human Ethics Committee in Arnhem-Nijmegen, the Netherlands (protocol number 2023–16249). The investigation did not fall under the legal mandates of the Medical Research Involving Human Subjects Act (WMO). Final reporting of the study data followed the EQUATOR network frameworks, explicitly the Consolidated Criteria for Reporting Qualitative Research (COREQ) [39].

Results and Discussion

The project synthesized data from multiple independent streams to construct a thorough understanding of the clinical indicators and symptoms that mark the transition into the palliative phase for individuals with COPD and HF. Data from the interviews and the rapid review were initially synthesized to find overlapping trends, which were mapped out into four core dimensions of palliative care (physical, psychological, social, and spiritual) [40, 41]. Crucially, moving into the palliative stage was not signaled by isolated indicators within a single domain, but rather by the concurrent manifestation and compounding accumulation of changes across multiple physical, psychological, social, and spiritual spheres, which were frequently paired with a rise in overall care demands.

A comprehensive breakdown of the study components, enrollees, and professional disciplines is provided in **Table 1**. **Table 1** displays the number and classification of participants or articles included in each research phase. For the qualitative interviews, nine community nursing practitioners provided deep, practice-based data. The rapid literature review synthesized 13 publications (10 systematic reviews, 2 integrative reviews, and 1 cohort study) that confirmed and refined the indicators identified during the interview phase. Eighteen professionals across two independent focus groups, representing a range of clinical roles, contributed multidisciplinary viewpoints to validate and expand the preliminary themes. Finally, 115 survey respondents helped prioritize and confirm the compiled indicators across an expanded sample of nursing professionals.

- Physical: symptom burden and functional decline
- Psychological: emotional and cognitive responses
- Social: relationships, roles, and support systems
- Spiritual: The spiritual dimension encompasses meaning and values, with existential concerns integral to this domain.
- Increasing care needs: increasing dependency and professional involvement

Table 1. Demographic characteristics of the participants. From: Signs and symptoms indicating the transition to the palliative phase in patients with COPD and heart failure in primary healthcare: a mixed-methods study.

Research method	Study period	Sample size	Participant characteristics/Study type	Average professional experience
Interviews	November 2022	9 participants	1 vocational nurse and 8 certified nursing assistants (CNAs)	Mean: 17 years
Rapid review	January–March 2023	13 studies	Included 10 systematic reviews (of which 2 incorporated meta-analyses), 2 integrative literature reviews, and 1 retrospective cohort study	—
Focus groups	April–May 2023	18 participants	Elderly care physician, spiritual caregiver, general practitioner, registered nurse (including pulmonary and palliative care specialists), vocational nurse, and certified nursing assistant	Mean: 26.5 years
Survey	April 2024	115 completed responses	Registered nurses, vocational nurses, nurse practitioners, and certified nursing assistants	Mean: 20.4 years

Physical dimension

Physical indicators consistently appeared across all four data streams as signs and symptoms marking the transition into the palliative stage for individuals with COPD and HF. During the personal interviews, community nursing staff reported directly observing clinical signs such as dyspnoea, unintentional weight loss, chronic fatigue, and functional decline. The rapid literature review corroborated these observations and highlighted distinct disease-specific warning signs, including fluid retention in HF patients and chronic, unmanaged dyspnoea in COPD patients. During the focus group sessions, nursing staff provided deeper descriptions of the physical decline they observed during routine care. While the individual indicators remained largely uniform, the group debates focused heavily on how these symptoms interact and compound over time. The quantitative survey outcomes validated and supported the ranking of these physical indicators. General symptom burden, dyspnoea, and acute exacerbation rates were most frequently highlighted as core indicators of the palliative transition, reflecting their perceived importance in everyday clinical practice.

Respondent 4 - Focus group: Practitioners frequently note indicators such as decreased body weight and disrupted sleep patterns in their patients.

Respondent 1 – Interview: Chronic fatigue, hypersomnia, and a general feeling of being overwhelmed are key indicators. For instance, heart failure patients exhaust rapidly when attempting to climb stairs, and their functional walking distance deteriorates continuously.

Respondent 8 – Focus group: A decline can sometimes be seen in the home environment itself. A patient who used to maintain an immaculate house might suddenly leave stacks of newspapers unorganized. They attempt to mask their struggles to preserve a sense of normalcy, even when they can no longer handle basic household tasks.

Across all research methodologies, physical deterioration was systematically documented during the transition to the palliative phase.

Psychological dimension

According to the participating nursing staff, psychological indicators in patients surfaced as critical, though frequently nuanced, warning signs of the shift into the palliative phase. The baseline qualitative interviews provided an open-ended exploration of clinician experiences, revealing psychological indicators such as anxiety, depressive symptoms, emotional exhaustion, and a sense of resignation. The rapid review subsequently confirmed and refined these findings within the wider medical literature, pointing to anxiety, depression, and emotional fatigue as frequently documented psychological signs in patient populations approaching the palliative stage.

During the focus groups, nursing staff expanded on these observations by analyzing how psychological transformations present in everyday care, frequently surfacing indirectly through patient withdrawal, decreased social engagement, or a loss of personal motivation. Finally, the survey validated these findings, with anxiety, depression, and emotional exhaustion ranked among the most critical psychological indicators of the palliative stage.

Respondent 7 – Interview: Patients exhibit significant anxiety regarding death, which is highly prevalent due to COPD, alongside profound sadness regarding the palliative transition.

Respondent 7 – Focus group: Prominent feelings include loneliness and grief over their lost identity and capabilities, which also impacts their relationships with partners.

Respondent 5 – Focus group: Patients occasionally engage in socially desirable behavior, masking their true condition to appear healthier than they actually are.

Social dimension

Interpersonal indicators indicate a gradual degradation of patients' social capabilities and relational frameworks. Initial qualitative interviews revealed that field nurses frequently witness a drop in recreational participation, a

heightened reliance on support networks, and visible psychological or physical strain among family caregivers. These field insights were supported by a rapid literature review, which confirmed that social isolation and informal caregiver burnout are recurring markers of the palliative phase across existing publications.

During focus group debates, clinical staff explained that shifts in the social realm typically manifest incrementally; for example, when an individual begins separating themselves from social circles or when relatives step in to shoulder a greater share of domestic duties. The quantitative survey subsequently established priorities for these relational markers, ranking structural adjustments in domestic roles, feeling too exhausted to sustain external relationships, and heightened friction or vulnerability within family networks as pivotal social indicators.

Respondent 3 – Focus group: Patients restrict their time outside the domestic environment, thereby contracting their network of acquaintances. As a consequence, friends must initiate visits, an activity that patients often find physically taxing.

Spiritual dimension

Existential warning signs initially appeared less prominent but grew increasingly vital as clear indicators of the transition toward a palliative framework. The baseline interviews yielded few direct references to spirituality, though subtle expressions of acceptance and a diminishing sense of personal purpose were recorded. The rapid literature review demonstrated that existential and spiritual themes—specifically the dread of mortality and the need to come to terms with finitude—are critical yet often unaddressed variables.

In the focus groups, existential signs became more explicit as clinicians analyzed patients' expressions of existential doubt about the meaning of life, personal legacy, and their prognosis. The survey verified that although spiritual components were less frequently prioritized than physical or psychological markers, they were recognized as indispensable to the comprehensive, holistic detection of the palliative stage.

Respondent 1 – Focus group: Individuals reflect on their remaining contribution, the value of their continued existence, and how to attain a state of peace and meaning, often through a spiritual lens.

Respondent 8 – Focus group: It is common for individuals to express a hidden dread of mortality, accompanied by internal reflections on the legacy of their lives and what truly matters to them.

Respondent 50 – Survey – open-ended response: Raising explicit inquiries regarding voluntary assisted dying.

Increasing care needs

This theme demonstrates how multi-dimensional decline manifests as compounding clinical demands, underscoring the deeply intertwined nature of physical, psychological, social, and spiritual deterioration. Across all evaluated data streams, an escalation in care complexity and intensity was systematically observed as individuals approached the palliative stage. This shift was characterized by a rising reliance on emergency medical services, unscheduled clinical interventions, recurrent (and frequently preventable) hospital readmissions, and the involvement of a broader range of healthcare practitioners. Nursing staff observed that, in retrospect, it became more obvious which individuals received futile medical interventions, given that their clinical trajectory had already entered the palliative phase.

Respondent 14 – Survey – open-ended response: The most critical indicator for me is an escalation in clinical appointments at the general practice or hospital. This includes a higher frequency of antibiotic prescriptions and, for heart failure populations, rapidly developing fluid overload again.

Respondent 4 – Focus group: Unremitting communication with their general practitioner alongside escalating rates of hospital admission.

The findings are detailed below across the five specific domains, prioritizing data compiled from all research streams. Within each domain, the documented signs and symptoms are outlined, accompanied by illustrative remarks that show how these features present in routine clinical practice. **Table 2** provides a comprehensive summary of the signs and symptoms most frequently recorded across the different data sources, categorized by the four dimensions of palliative care and compounding care requirements.

Table 2. Multi-dimensional signs and symptoms of transition to palliative care. From: Signs and symptoms indicating the transition to the palliative phase in patients with COPD and heart failure in primary healthcare: a mixed-methods study.

Domain	Representative signs and symptoms
Physical	Shortness of breath (dyspnea), fatigue, declining functional ability, recurrent exacerbations, fluid accumulation (heart failure), weight loss, pain, and dependence on oxygen therapy
Psychological	Anxiety, depressive symptoms, fear of dying, emotional fatigue, resignation, and diminished desire to continue living
Social	Reduced participation in daily and social activities, growing dependence on caregiving, caregiver burden, and increased reliance on informal caregivers or observers
Spiritual	Existential suffering, loss of meaning in life, questioning one's purpose, and fear of death
Escalating care needs	Greater utilization of acute healthcare services, more frequent unplanned interventions, hospital admissions, and involvement of multiple healthcare professionals

The complete findings regarding the identified signs and symptoms, documented in Dutch, are available upon request from the corresponding author.

This investigation demonstrates that healthcare providers, particularly community-based nursing staff, are capable of articulating distinct and identifiable indicators when explicitly questioned about the transition to the palliative stage in individuals with COPD and heart failure. These signs and symptoms are the precise markers that clinicians associate with this transition during routine care. By converting this largely intuitive clinical expertise into explicit data, the study offers practice-grounded insight into how the palliative phase is recognized in daily workflows.

Using an integrated mixed-methods design, we identified and prioritized indicators across the physical, psychological, social, and spiritual dimensions, alongside escalating healthcare needs. These observations highlight the sophisticated clinical reasoning required to detect the palliative phase and to establish an organized framework that facilitates timely identification within community care.

While this project does not test specific clinical interventions, the documented signs and symptoms can guide the future engineering of ML-driven decision-support software designed to aid nursing staff in detecting the palliative stage and launching a comprehensive palliative strategy, inclusive of ACP.

Multi-dimensional nature of deterioration

The shift toward the palliative stage involves multiple interconnected domains. Physical markers such as dyspnoea, fatigue, and functional decline were systematically emphasized, reflecting the progressive trajectory of COPD and HF detailed in prior literature [41-43]. Recently, Gebresillassie *et al*. [44] identified six primary prognostic factors in individuals with COPD, which primarily track with physical decline and could help clinicians identify the palliative phase earlier. These variables largely align with the signs and symptoms mapped out in our project.

Psychological indicators, including anxiety, depressive symptoms, fear of isolation, and a diminishing will to live, were frequently reported. A longitudinal study tracking individuals with HF, their family caregivers, and healthcare practitioners demonstrated that HF strains numerous facets of daily life and induces persistent psychological suffering [45]. According to Remawi *et al*. [45], patients and informal caregivers frequently struggle to adapt to the disease and determine the appropriate time to initiate palliative services. Healthcare professionals found it difficult to identify the palliative phase and start these dialogues. Both groups highlighted the necessity for transparent communication, emotional support, and enhanced care coordination. Psychological distress frequently surfaces early in the disease trajectory, emphasizing the value of incorporating mental health markers into nursing assessments and diagnostic prediction tools.

Social decline was characterized by a withdrawal from routine activities, a loss of functional autonomy, and an increased reliance on external support systems. Corresponding with historical data, patients experienced a progressive narrowing of their social ecosystem as physical restrictions and shifting symptom severity limited their involvement in daily life [46]. In an investigation by Suen *et al*. [47], nearly one in six adults with COPD experienced social isolation, and one in five reported loneliness—rates that are roughly twice as high among individuals dependent on supplemental oxygen compared to the general population. Recurrent hospitalizations and the constant burden of symptom control further exacerbated feelings of isolation. Although family members frequently offer critical help, their intervention can sometimes inadvertently deepen patient dependence and compromise personal autonomy [47]. Managing the social ramifications of chronic illness is therefore vital to providing genuinely holistic care.

Although spiritual matters appeared less pronounced in this study, the interviews and focus groups exposed existential suffering and a loss of personal meaning. Historical literature has also detailed an incremental decline in spiritual well-being among individuals with HF, which was tied to identity loss and functional dependence [46]. Many individuals questioned their value and role in the world as their illness advanced, matching the trends observed in our project. Patients who felt validated by their healthcare providers were better equipped to preserve self-worth and reach acceptance. This insight underscores the importance of incorporating spiritual support into the palliative phase.

Escalating care requirements, evidenced by unscheduled hospitalizations and emergency interventions, further demonstrate the fluid, multi-causal nature of disease courses in patients with COPD or HF. Crucially, patients who receive palliative services or participate in ACP generally experience fewer intensive care unit (ICU) admissions and shorter lengths of stay, as demonstrated in a systematic review by Khandelwal *et al*. [48], underscoring the capacity of timely palliative actions to mitigate unwanted intensive care utilization while sustaining patient-centered care [48].

Value of the nursing perspective

This investigation integrated several clinical viewpoints, but the nursing perspective proved exceptionally vital for understanding and identifying the transition into the palliative phase. Nurses routinely spend the most time with patients, allowing them to spot subtle physical, psychological, and social variations during daily care that

might mask early decline. Their ongoing contact and holistic methodology offer vital contextual data that complement biomedical and disease-specific parameters [49].

The observations from this project will guide the future design of an ML instrument for integration into electronic patient health records. Embedding nursing observations and clinical reasoning into this type of tool can maximize its clinical relevance, operational utility, and contextual validity [50], ensuring that predictive assistance aligns with nursing workflows and fosters earlier, more patient-aligned recognition of palliative needs. Although the focus of this study was centered on community nursing workflows, the documented multi-dimensional signs and symptoms are not profession-specific. These indicators could also facilitate earlier detection of palliative requirements by other clinicians managing patients with COPD and HF—such as physicians and physical therapists—particularly when operating within multidisciplinary or community-based networks. Formally defining these shared indicators may improve interprofessional communication and coordinated palliative care delivery.

Implications for future decision-support approaches in home-based nursing care

In this study, the documented signs and symptoms are proposed as data inputs for a machine learning–driven decision-support feature embedded directly within the EHR utilized in community nursing, rather than functioning as an isolated tool. In current clinical workflows, tools such as the Supportive and Palliative Care Indicators Tool (SPICT) and the Surprise Question facilitate recognition of palliative care needs. Still, these instruments are frequently constrained in their scope and validation for individuals with chronic HF and COPD, particularly concerning multi-dimensional and non-physical requirements [15, 51].

Addressing these constraints of current instruments, the complete set of compiled signs and symptoms clustered into five themes, four domains of palliative care, and the rising care demands identified in this project establishes a robust framework for engineering an ML-driven strategy to support timely identification of the palliative phase. Coding these signs and symptoms into an algorithmic model could mirror the complex decision-making processes of community nurses, potentially unlocking earlier, more personalized palliative management. However, introducing ML into home-based care also introduces ethical and logistical dilemmas. Guaranteeing explainability and transparency is vital so that nursing staff comprehend algorithmic alerts while retaining clinical accountability for final decisions [52]. Although the algorithm does not require additional storage architectures, it processes sensitive patient information that is already logged in the electronic health record. Consequently, data privacy and security protocols must be implemented, especially given the vulnerability of these patient cohorts [53].

Additionally, software designed to identify the palliative phase must be structured to integrate seamlessly into existing workflows, reinforcing community nurses' clinical judgment rather than overriding it. Therefore, generating supplementary administrative burden must be avoided [54]. Regarding ethical considerations, implementation requires close attention to equity and algorithmic bias, ensuring that predictive tools do not inadvertently marginalize underrepresented patient groups [55]. Embedding ML within electronic health documentation offers practical integration while protecting both patient-centered care and professional nursing autonomy.

Strengths and limitations

This investigation has several significant advantages. By centering the research on home-based care, the outcomes remain highly applicable to home care environments. Utilizing a mixed-methods approach enabled effective data triangulation, yielding a more profound and detailed comprehension of the indicators characterizing a patient's shift into the palliative stage. A major advantage was the thorough collaboration with end users: interviewing nursing staff across various teams within two distinct home-based care institutions ensured that practical, hands-on expertise directly shaped the final results. Furthermore, the active participation of multidisciplinary healthcare professionals in the focus groups ensured the capture of varied perspectives and functional viewpoints. The project also methodically investigated casual and formal terminology, as well as personnel's personal accounts, supplementing existing literature that frequently relies on scholastic or formal frameworks, thereby firmly rooting this inquiry in routine professional operations.

Weaknesses include restricting the sample to only two home care institutions, potentially limiting the breadth of institutional viewpoints. Although the two focus groups comprised 16 individuals in total, the broad range of professional fields represented suggests that the unique viewpoints of each participant may not have been exhaustively investigated.

While a junior and a senior investigator designed and piloted the questionnaire to evaluate its comprehensibility and practicality, this stage was limited in scope. It lacked a structured verification of content validity or stability, an oversight that could impact the overall strength of the survey architecture.

Furthermore, the secondary literature analysis was conducted as a rapid review; though this approach optimized efficiency, it may not have encompassed the full published data.

Future directions

Subsequent inquiries should focus on the step-by-step development, analysis, and implementation of ML-driven identification software within routine clinical operations, in accordance with the Medical Research Council (MRC) guidelines for complex interventions [56]. Preliminary feasibility assessments must analyze the assimilation into existing workflows, user experience, adherence to ethical principles, and primary performance metrics, including forecasting precision, clinical outcomes, and staff adoption. Ensuing investigations should verify the performance of these digital tools across various medical environments and client demographics, while continuing to emphasize the multi-faceted character of patient decline to guarantee ethical, holistic, and patient-aligned clinical management.

Conclusion

This research effectively mapped and ranked critical indicators spanning physical, psychological, social, and spiritual spheres, alongside rising clinical burdens, that signify a shift into the palliative stage for individuals diagnosed with COPD and HF. These insights provide an exhaustive baseline for engineering an ML framework to help community nursing staff detect this clinical phase promptly, thereby encouraging the launch of comprehensive home palliative strategies, such as ACP. Prompt detection driven by these multi-dimensional indicators can eventually optimize patient-aligned, forward-looking, and comprehensive palliative management within home-based environments.

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