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When Digital Silence Does Not Mean Symptom Stability: A Methodological Framework for Interpreting Missing Patient-Reported Data in Remote Palliative Nursing Assessment and Follow-Up

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Abstract

To develop a method for interpreting missing patient-reported symptom data during remote palliative nursing assessment without treating digital nonresponse as evidence of clinical stability. Remote symptom monitoring can extend palliative assessment beyond scheduled encounters, but it also creates an interpretive problem when an expected patient report is absent. Advanced illness, fluctuating capacity, respondent burden, language, technology access, service workflow and patient preference can all influence whether a report becomes observable. Original non-empirical methodological framework informed by selected palliative-care outcome-measurement research, remote symptom-monitoring studies, implementation evidence, digital-equity literature and missing-data methodology. Evidence published between 2017 and 2025 was used to distinguish measurement of observed symptoms from the interpretation of unobserved patient states and to identify circumstances in which missingness may be clinically or methodologically informative. The approach treats the expected assessment opportunity, rather than a fixed patient category of "responder" or "nonresponder," as the unit of analysis. It separates observed patient reports from unobserved symptom states and requires the reason for missingness to remain provisional when inability to report, failed contact, refusal or nonparticipation, and technical or access failure cannot be distinguished. Digital silence is an information gap, not a symptom value. Remote palliative nursing systems should preserve uncertainty until the source and meaning of a missing report can be sufficiently established.

Keywords: Nursing, Palliative care, Patient-reported outcomes, Remote symptom monitoring, Missing data, Digital health

Introduction

Electronic patient-reported outcome monitoring is increasingly incorporated into cancer and supportive-care services, creating opportunities for symptoms to be assessed between conventional encounters [1]. Remote delivery does not itself imply inferior palliative care: in a large multisite trial of adults with advanced lung cancer, video-based early palliative care achieved patient quality-of-life outcomes comparable with in-person care, although caregiver participation differed between modalities [2]. The methodological difficulty therefore lies less in whether remote assessment is possible than in what clinicians may legitimately conclude when an expected report never becomes available.

That distinction matters because remote monitoring systems are usually designed as active clinical processes. In one randomized model, repeated Integrated Palliative care Outcome Scale assessments were linked to nurse review, treatment and referral, yet the intervention did not improve overall quality of life or several utilization

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outcomes [3]. A broader meta-analysis similarly found that patient-reported outcome interventions had heterogeneous effects across quality-of-life, survival and healthcare-use endpoints [4]. The existence of a digital monitoring channel therefore neither guarantees benefit nor makes every gap in that channel clinically interpretable.

For palliative nursing, the central problem is epistemic and practical. A completed report supplies patient-attributed information at a defined time. A missing report supplies no equivalent symptom value. If absence is silently translated into "no change," patients who are too unwell to report, cannot be reached, decline participation or encounter technical barriers may be misclassified as clinically stable. The purpose of this paper is to establish a missingness-aware methodology that keeps these possibilities separate until enough contextual evidence exists to support a stronger interpretation.

Background

Palliative patient-reported outcome measures are designed to represent concerns that patients or, where appropriate, proxies actually report. The Integrated Palliative care Outcome Scale has demonstrated validity, reliability and responsiveness in advanced illness, while Rasch analysis has also shown that measurement structure and item behaviour require careful interpretation [5, 6]. These psychometric properties concern the quality of information that is obtained; they do not convert an absent assessment into an observed symptom state.

Repeated remote completion is also variable. In advanced cancer, weekly electronic IPOS assessment has been feasible for many patients, but completion was not universal and some participants experienced the process as burdensome [7]. Implementation work in outpatient palliative oncology likewise shows that electronic administration can expand data availability while still requiring paper alternatives or other accommodations for patients who cannot or do not complete an electronic instrument [8]. Thus, the availability of patient-reported data depends partly on the fit between illness, reporting demands and mode of administration.

The assessment environment can further change what becomes observable. During a period of heavy telehealth use in inpatient palliative care, documentation of some physical and psychological domains was less complete than in predominantly in-person periods, although the comparison was observational and occurred during a pandemic disruption [9]. This finding does not establish that telehealth is intrinsically deficient. It demonstrates that mode, workflow and contextual strain can alter the evidentiary record from which clinicians later reason.

For remote palliative nursing, the relevant methodological distinction is therefore between an expected assessment opportunity, the information actually obtained, and the information that remains unavailable. A clinically meaningful missingness method must retain these states separately before asking why an expected report is missing.

Table 1 distinguishes the observation conditions that arise before any inference about the patient's symptom trajectory is made.

Table 1. Observation conditions surrounding an expected remote patient-reported symptom assessment

Assessment condition	What is directly observable	What remains unobserved	Potential origin of missing patient report	Permissible interpretation at this stage
Patient report completed	Patient-attributed symptom information at the assessment time	Unmeasured symptoms or later change	None for the completed items; item-level omissions may remain	Interpret submitted responses within instrument and clinical context
Patient report started but incomplete	Submitted items and evidence of partial engagement	Missing items and reason for discontinuation	Burden, illness interruption, interface difficulty, choice or other cause	Do not assign values to unanswered items without justified analytic handling
Patient contact occurs but self-report is not obtainable	Contact, encounter and any separately documented clinical observations	Patient-reported symptom state	Temporary inability, severe illness, communication barrier, preference or other cause	Record source-specific observations; do not label them as patient-reported data
Assessment occurs through another modality	Information obtained through telephone, paper, proxy or clinician contact	The originally expected electronic report	Mode substitution, access limitation or patient preference	Treat the alternative source according to its provenance rather than as an electronic response
Expected contact or assessment does not occur	The scheduled or expected assessment opportunity and its noncompletion	Current symptom state and often the reason for noncompletion	Failed reach, service process failure, illness, disengagement or unknown cause	Maintain symptom state as unobserved until contextual evidence reduces uncertainty

Technical transaction fails or cannot be confirmed	Platform or transmission failure, when logged	Patient symptom state and sometimes whether reporting was attempted	Device, connectivity, authentication, portal or system failure	Interpret as a data-acquisition problem unless separate clinical information is available

Data sources

The methodological argument draws first on intervention studies in which patient-reported symptoms are repeatedly collected and linked to clinical response. Large randomized studies of electronic symptom monitoring show that remote reporting can be embedded in routine oncology practice and can influence communication, symptom management or care processes [10]. However, positive findings cannot be assumed across settings. Among hospitalized patients with advanced cancer, a symptom-monitoring intervention did not significantly improve the main symptom, length-of-stay or readmission outcomes examined [11]. This null evidence is important because it prevents the presence of additional symptom data from being treated as inherently beneficial.

A second evidence stream concerns real-time and workflow-integrated monitoring. The eSMART trial demonstrated a multicentre model in which patients receiving chemotherapy reported symptoms remotely during treatment [12]. The eRAPID programme likewise integrated electronic patient-reported symptom information into routine cancer care [13]. Such systems establish an important methodological principle: a reported symptom becomes clinically useful through a chain that includes acquisition, review and response. The clinical pathway begins with an observation that actually exists.

Earlier randomized evidence also showed that routine electronic symptom monitoring could be associated with meaningful downstream outcomes, including a survival advantage in a cancer-treatment trial [14]. That result strengthens the argument for taking patient-generated symptom information seriously. It does not justify reversing the logic and treating the absence of a report as if it were a measured exposure, symptom score or prognostic indicator.

Accordingly, four evidence domains are used in this article for different purposes. Palliative outcome-measurement research establishes what patient- and proxy-reported observations can represent. Remote monitoring trials show how submitted reports enter clinical workflows. Implementation and equity research identifies circumstances that affect whether reporting can occur. Missing-data methodology addresses what can and cannot be inferred once an expected observation is unavailable. These domains are complementary, but none individually establishes the meaning of a missing patient report.

Figure 1 summarizes this evidence architecture by separating the assessment opportunity, the information channel and the interpretation boundary before any missingness mechanism is assigned.

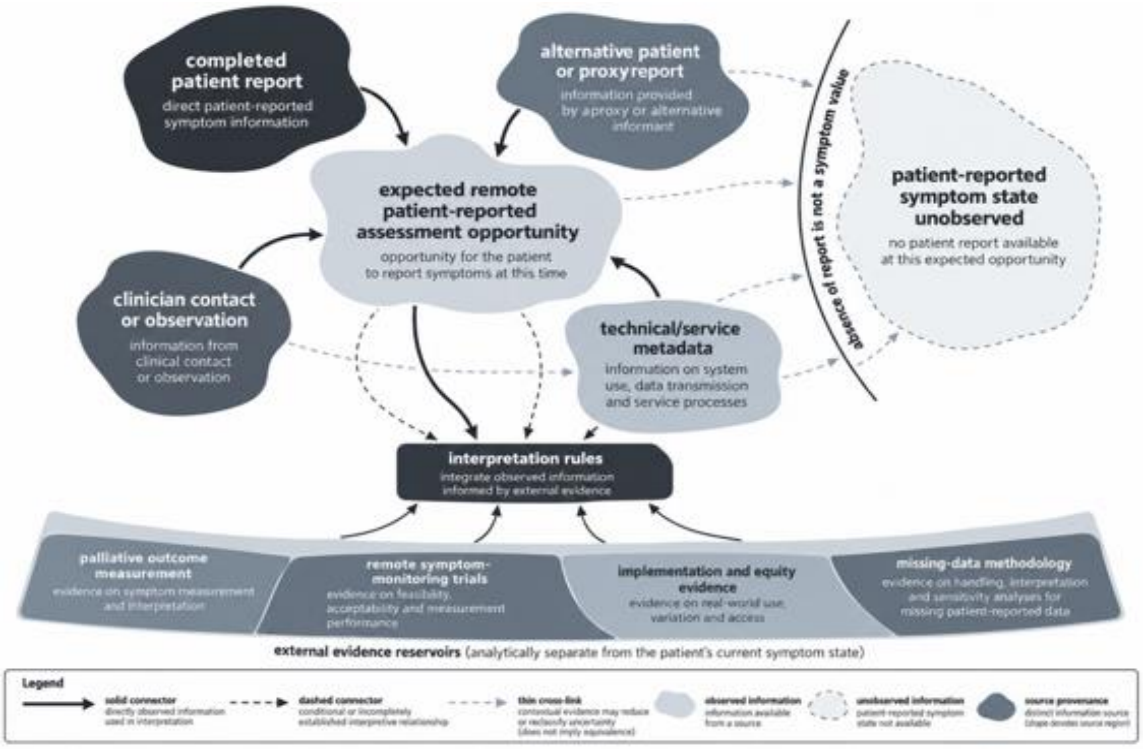


Figure 1. From expected assessment opportunity to interpretable evidence in remote palliative symptom monitoring

Overview of the issues

A missing expected report can be generated at several points in the remote-care process. Access is one source of variation. In ambulatory palliative oncology, telemedicine use differed according to factors including language, insurance status and portal activation [15]. Such associations do not identify the cause of an individual patient's nonresponse, but they show that availability of digital information is not socially or technically neutral.

Failure to obtain follow-up may also occur at the level of service contact. A large outpatient palliative-care cohort demonstrated differences in completion of initial and follow-up encounters across demographic and clinical characteristics [16]. For a remote assessment methodology, this supports a distinction between a patient who was contacted but did not provide a report and a patient whose intended contact was never successfully completed. Both produce missing patient-reported data, but they represent different observational failures.

Language creates another source of ambiguity. Qualitative research among seriously ill patients and caregivers who preferred Cantonese or Spanish identified difficulties with portals, between-visit communication and interpreted telehealth, while also showing that remote care itself could remain acceptable and valuable [17]. Digital silence in such circumstances may arise from communication infrastructure rather than symptom state. Similarly, eHealth literacy and preferences vary among patients, caregivers and healthcare professionals [18]. Limited digital capability, preference for another modality and deliberate nonparticipation therefore cannot be collapsed into a single explanation.

Routine ePROM programmes further show that participation is selective rather than universal [19]. Selection may reflect patient characteristics, illness, service design, reporting burden, technology or preference. At the organizational level, qualitative implementation work has identified workflow, infrastructure, resources, trust and local context as influences on whether remote symptom-management systems are used successfully [20]. A missing report can consequently originate beyond the patient even when the record superficially appears as "patient nonresponse."

The interpretive problem becomes more complex because electronic patient-reported outcome systems are multi-component interventions. Realist synthesis indicates that self-reporting, clinician feedback and communication mechanisms interact to produce benefit or failure [21-23]. If a report is absent, the missing event may represent interruption at the level of patient reporting, digital transmission, service reach, clinician workflow or a combination of these. The same visible endpoint—no submitted report—can therefore arise from clinically different processes.

For the present methodology, four mechanism families are provisionally useful: unable to report, not reached, refusal or nonparticipation, and technical or access failure. They are not asserted as mutually exclusive validated categories. A patient may be too unwell to use a portal while also having poor connectivity; a person who initially declines reporting may later participate; an apparently technical failure may conceal an uncompleted outreach process. Where evidence does not distinguish these possibilities, the appropriate classification is mixed or unresolved rather than forced certainty.

Table 2 organizes these competing explanations around what can actually be observed and, equally important, what must remain uninterpreted until additional information is available.

Table 2. Competing mechanisms of digital silence in remote palliative symptom follow-up

Provisional mechanism	Observable clues that may support consideration	Important competing explanations	What cannot be inferred from the missing report alone	Documentation priority
Unable to report	Known acute illness, reduced functional capacity, communication difficulty, interrupted attempt or contemporaneous clinical concern	Temporary technology problem, fatigue, preference for another modality, failed reach	Symptom severity, direction of change, prognosis or patient preference	Record why self-report was not obtainable and identify any alternative information source
Not reached	Unanswered outreach, failed scheduled contact, unavailable communication channel or uncompleted follow-up process	Hospitalization, changed contact details, technical failure, intentional nonresponse	Refusal, symptom stability or deterioration	Distinguish attempted contact from successful contact and record subsequent reach attempts or known care transitions
Refusal or nonparticipation	Explicit decline, stated preference not to use the tool, withdrawal from repeated reporting or preference for another mode	Burden, cognitive or physical difficulty, mistrust, language/access barriers	Lack of symptoms or lack of need for care	Preserve the patient's stated preference and avoid recoding it as inability or technical failure

Technical or access failure	Portal error, authentication problem, device or connectivity limitation, failed transmission or unavailable digital access	Incomplete outreach, low digital literacy, illness-related inability, preference	Any current symptom state	Record the technical event separately from the clinical record and use an alternative communication route where appropriate
Mixed or unresolved	Conflicting, incomplete or changing contextual information	Any combination of the other mechanisms	A single definitive reason for silence	Retain uncertainty explicitly until additional evidence supports reclassification

The central implication is that a missing remote assessment should initially be treated as an unobserved patient-reported state with an uncertain mechanism. The next methodological task is therefore not to assign a symptom value to silence, but to determine how far available contextual information can reduce that uncertainty without substituting one source of evidence for another.

Methodological framework

The unit of analysis is the expected remote assessment opportunity: a defined point at which patient-reported symptom information was intended to become available. This episode-based unit avoids treating "responder" and "nonresponder" as stable patient identities. Remote monitoring research shows that information becomes clinically meaningful through communication between patients and clinicians rather than through data acquisition alone [24]. Each assessment opportunity should therefore be interpreted according to what information was expected, what was actually observed, from whom it originated and what remains unknown.

A completed patient report can legitimately enter a triage or review pathway because an observation exists. Digital palliative interventions such as ePAL demonstrate how submitted symptom information can be linked to assessment, education and clinical response [25]. An absent report lacks that evidentiary property. Its missingness may itself require attention, but no symptom magnitude, direction of change or risk level should be assigned simply because the reporting event failed to occur.

Source attribution is equally important. Patient report, proxy report and clinician assessment may be clinically complementary while remaining methodologically distinct. Validation research comparing patient-reported measures with multidisciplinary palliative assessment demonstrates that patient-generated information can contribute to identifying need without becoming interchangeable with clinical judgment [26]. When alternative information is obtained after a missing patient report, the record should preserve who supplied it and what it represents.

The strongest empirical reason to retain uncertainty comes from research on informative missingness. In advanced cancer datasets, patients who did not return quality-of-life questionnaires were estimated to have poorer quality of life than respondents under some analyses, yet the magnitude and pattern changed with modelling and temporal assumptions [27]. Missingness can therefore contain information about prognosis, illness burden or participation processes at the population level while remaining insufficient to determine an individual patient's current symptom state.

Statistical handling and clinical interpretation must consequently remain separate. Multiple-imputation methods can reduce bias in research datasets when their assumptions are defensible [28]. They do not reconstruct the patient's actual experience at a missed assessment and cannot substitute for clinical contact. A nursing record should not transform a statistically imputed value into a patient-reported symptom observation.

Timing also matters. Missing patient-reported information may become more common as illness progresses, treatment toxicity develops or follow-up becomes difficult. Methodological work on early censoring in health-related quality-of-life research illustrates why apparently acceptable completion rates may still conceal informative loss of observations [29]. Remote palliative assessment should therefore document missingness longitudinally rather than interpreting isolated completion percentages as evidence that missing reports are ignorable.

International PRO methodology supports transparent prespecification, sensitivity analysis and cautious interpretation when data are incomplete [30-32]. Applied to remote palliative nursing, these principles imply that the expected reporting interval, permitted reporting routes, source of substitute information, known reason for missingness and degree of interpretive uncertainty should be defined explicitly. This adaptation is methodological rather than a claim that oncology trial standards themselves validate a clinical follow-up algorithm.

Protocol guidance for patient-reported outcomes similarly emphasizes planning for data collection and missing data before analysis [33]. In practice, the reason for a missing remote report will sometimes remain unknown despite documentation efforts. The methodology therefore permits five working states: unable to report, not

reached, refusal or nonparticipation, technical or access failure, and mixed or unresolved. These states describe the reporting process. They do not diagnose symptom severity.

Results and Discussion

Missing patient-reported information is frequently treated too casually in health research. A methodological review of oncology trials found that recommended reporting and assessment of missing quality-of-life data were uncommon, leaving informative censoring difficult to exclude in many studies [34]. Remote palliative care faces a related problem at the level of individual assessment: when clinicians cannot establish why an expected report is absent, confidence in conclusions based on that absence should remain limited.

Respondent burden adds an important ethical dimension. Repeated questionnaires can impose cognitive, physical and emotional demands, particularly for people living with advanced illness. Methodological guidance on PRO burden therefore recommends minimizing unnecessary assessment and recognizing burden as a contributor to incomplete data [35]. In palliative nursing, a missing report may arise because participation has become difficult or unwanted. Repeated escalation without considering that possibility could undermine autonomy even when motivated by safety.

Table 3 translates the framework into an interpretation-and-follow-up matrix without assigning numerical urgency thresholds.

Table 3. Interpretation and follow-up considerations when an expected remote symptom report is missing

Current evidentiary state	Immediate interpretation	Information that may reduce uncertainty	Appropriate methodological response	Interpretation that should be avoided
Patient known to be temporarily unable to self-report	Patient-reported state unavailable	Proxy information, clinician contact, recent care transition, subsequent self-report	Preserve source attribution and document temporary inability	Treating proxy or clinician observation as if it were the patient's own report
Expected outreach unsuccessful	Current patient-reported state unknown	Repeat contact, alternate approved contact route, known hospitalization or transfer	Record failed reach and whether uncertainty was later resolved	Coding failed contact as refusal or stability
Explicit nonparticipation or refusal	No report by patient choice at that time	Stated preference, alternative acceptable reporting method, later change in preference	Respect preference and document the chosen communication arrangement	Interpreting refusal as absence of symptoms
Confirmed technical/access failure	Clinical state unknown through the failed channel	Alternate platform, telephone, paper, interpreter-supported or in-person contact	Separate technical failure from clinical assessment	Assigning clinical significance to the technical event itself
Mechanism unclear or mixed	Symptom state and reason for missingness remain uncertain	Multiple contextual sources and subsequent assessments	Retain unresolved status and reassess interpretation when evidence changes	Forcing the episode into a single mechanism category

Digital inequity intensifies the risk of misinterpretation. Telemedicine success has been shown to vary across patient groups, and unsuccessful encounters have been associated with adverse outcomes in thoracic cancer populations [36]. Together with evidence on language, portal access and implementation barriers, this indicates that observability itself can be unequally distributed. A remote monitoring system may therefore generate apparently complete information for patients who are easiest to reach while producing uncertainty for those facing the greatest access barriers.

Follow-up should respond to the amount and type of uncertainty present. A recent clinician encounter, proxy report or verified technical failure may narrow possible explanations without recreating the missing patient report. Conversely, repeated failed contact combined with worsening illness context may justify greater concern, while still leaving the current patient-reported symptom state unobserved. The proposed approach therefore uses contextual evidence to refine the reason for missingness and the need for further assessment, rather than to manufacture a symptom value.

Figure 2 represents this uncertainty-preserving process across follow-up.

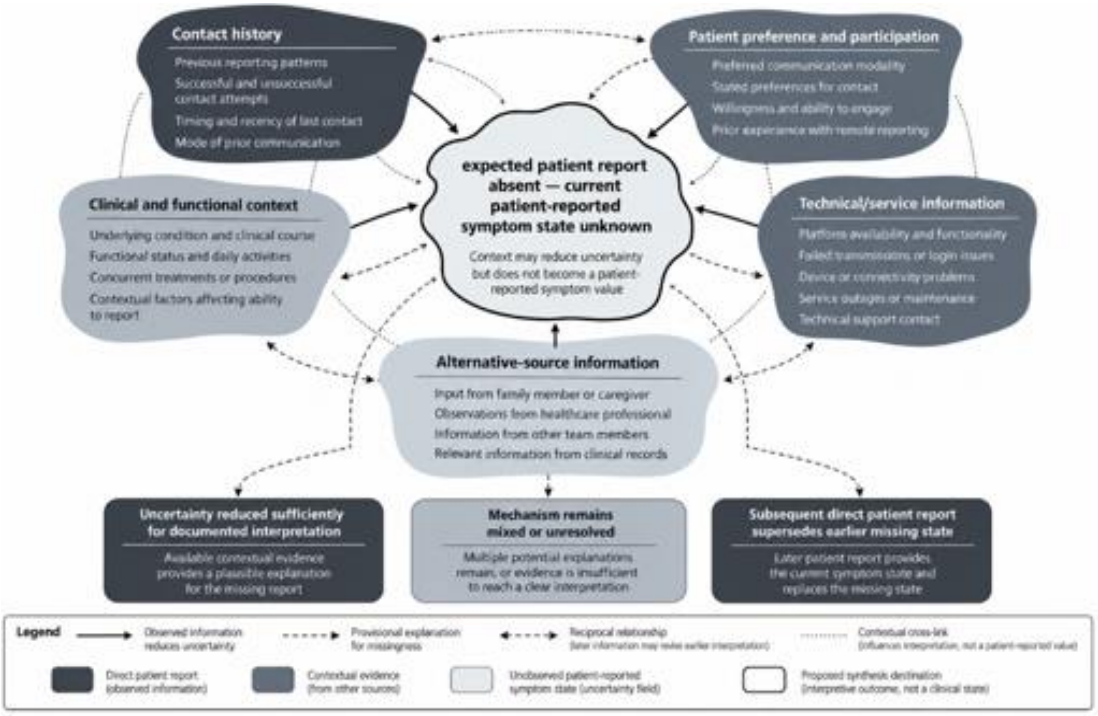


Figure 2. Preserving uncertainty while interpreting digital silence across remote palliative follow-up

The framework is deliberately provisional. The mechanism families should not become diagnostic labels attached permanently to patients. A patient may move from technical failure to successful reporting, from refusal to later participation, or from apparent nonresponse to documented inability as illness changes. Informative missingness research similarly shows that the interpretation of incomplete PRO data depends on time, assumptions and available contextual information [27]. Classification should therefore remain episode-specific and revisable.

Empirical validation is required before this methodology is treated as a clinical standard. Research should examine whether clinicians can classify missingness consistently, whether documenting reasons is feasible, whether follow-up improves information quality, and whether the method reduces disparities without increasing burden. Implementation research already shows that organisational resources and workflows strongly shape ePRO use [23], while international PRO standards emphasize transparent analysis and interpretation [31]. Validation should consequently include diverse palliative settings rather than a single digital platform or cancer population.

Table 4 distinguishes safeguards that can be applied immediately as methodological disciplines from questions that still require empirical testing.

Table 4. Methodological safeguards and empirical validation requirements for missingness-aware remote palliative assessment

Methodological domain	Safeguard available now	Unresolved validation question
Observation status	Keep observed patient report separate from unobserved state	Can clinicians apply this distinction consistently in routine documentation?
Source attribution	Record whether information comes from patient, proxy, clinician or service/technical data	How does source-specific documentation affect decision quality and workload?
Missingness mechanism	Use provisional mechanism categories and allow mixed or unresolved status	Are the categories reliable, sufficiently complete and transferable across settings?
Longitudinal interpretation	Reclassify episodes when new evidence becomes available	What follow-up interval and intensity are feasible and safe in different services?
Equity	Treat access, language and technology as determinants of observability	Does the methodology reduce or inadvertently reproduce digital disparities?
Patient burden	Respect refusal and consider reporting burden when assessments are repeatedly missed	How should systems balance information needs with burden in advanced illness?

Clinical translation	Avoid converting missingness into symptom values or numerical risk estimates	What clinical outcomes, if any, improve when missingness-aware assessment is implemented?

Conclusion

Remote palliative nursing increasingly depends on patient-generated information that may not always arrive when expected. A missing report should therefore be documented first as an unobserved patient-reported state, with its cause investigated without assuming stability, deterioration, refusal or technical failure. Distinguishing inability to report, failed reach, nonparticipation and access failure preserves clinically important uncertainty while allowing later evidence to refine interpretation. The central methodological principle is simple: digital silence can be informative, but it is not itself a symptom observation. Safe use of this approach now requires empirical validation across populations, technologies and palliative-care settings.

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