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Electronic symptom monitoring for home-based palliative care: A systematic review

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Abstract

Background: Coordination and communication challenges in home-based palliative care complicate transitions from hospital care. Electronic symptom monitoring enables real-time data collection, enhancing patient-provider communication. However, a systematic evaluation of its effectiveness in home-based palliative care is lacking.

Aim: To analyze the feasibility, effectiveness, and limitations of electronic symptom monitoring in home-based palliative care, assess the evidence quality, identify the evidence gap, and suggest implications for future research and practice.

Design: This study uses systematic review, meta-analysis, and narrative synthesis (CRD42023457977) to analyze relevant studies until September 2023.

Data sources: Electronic searches in MEDLINE, CENTRAL, and Embase until September 2023, complemented by hand-searching of references and citations.

Results: This study included twenty studies. The majority of patients positively engage in electronic symptom monitoring, which could improve their quality of life, physical and emotional well-being, and symptom scores without a significant increase in costs. However, firm conclusions about the effects of electronic symptom monitoring on outcomes like survival, hospital admissions, length of stay, emergency visits, and adverse events were limited due to significant variability in the reported data or inadequate statistical power.

Conclusion: Introducing electronic symptom monitoring in home-based palliative care holds potential for enhancing patient-reported outcomes, potentially decreasing hospital visits and costs. However, inconsistency in current studies arising from diverse monitoring systems obstructs comparability. To advance, future high-quality research should employ standardized follow-up periods and established scales to better grasp the benefits of electronic symptom monitoring in home-based palliative care.

Keywords

Patient reported outcome measures, telemedicine, palliative care, information technology, quality of life, systematic review

What is already known about the topic?

- Home-based palliative care has grown in popularity, but challenges in coordinating care and communication between hospital and home settings can impact transitions, healthcare consumption, care quality, and patient safety.
- Electronic symptom monitoring systems in home-based palliative care utilize telemedicine to remotely collect real-time symptom data, offering flexible feedback to patients and healthcare providers during clinical consultations.

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What this paper adds?

- Most patients positively engage in electronic symptom monitoring, potentially enhancing quality of life, physical and emotional well-being, and symptom scores without significant cost increase.
- Definitive conclusions regarding the impact of electronic symptom monitoring on outcomes such as survival, hospital admissions, length of stays, emergency visits, and adverse events were constrained by substantial variability in reported data or inadequate statistical power.

Implications for practice, theory, or policy

- Future high-quality randomized controlled trials or large-scale real-world studies on electronic symptom monitoring in home-based palliative care should assess its short-, medium-, and long-term effects on both cancer and non-cancer populations.
- Employing globally recognized patient-reported outcome scales like the EORTC Core Quality of Life Questionnaire and the 36-item Short Form Health Survey guarantees reliable and generalizable results in accurately assessing symptoms and enabling meta-analysis.
- Incorporating electronic symptom monitoring into home-based palliative care should prioritize accessibility, feasibility, and patient acceptance, particularly in uncertain clinical scenarios.

Introduction

Electronic symptom monitoring involves using questionnaires distributed to patients through electronic systems, such as the World Wide Web, a smartphone app, or an automated telephone interface, to gather patient-reported outcomes (PROs).[1] A PRO constitutes any direct report from a patient on their health status, without interpretation by a clinician or others, and is typically assessed through patient-reported outcome measures (PROMs), often in the form of self-report questionnaires.[2] Electronic symptom monitoring streamlines symptom reporting, allows for remote data collection, and facilitates patient-provider communication regarding symptoms[3,4] (Supplemental File 1), potentially impacting clinical decision-making significantly.

Electronic symptom monitoring systems exhibit three key characteristics. Firstly, the "electronic" aspect involves data collection in a telemedicine fashion, bypassing the use of paper or routine clinical visit. Secondly, focusing on "symptom," these systems gather subjective symptoms reported directly by patients, as opposed to objective signs reflecting physiological functions. They do not rely on wearable or implantable sensors for automatic vital sign tracking.[5] Electronic monitoring systems could alert health professionals about severe symptoms reported by patients.[1,6] Lastly, under "monitoring," the emphasis is on the essential patient-healthcare interaction, distinguishing them from self-management tools like diary applications.[7]

Palliative care emphasizes responsiveness to individual patient needs and preferences,[8] which aligns with the global efforts by the WHO to improve access to and provision of palliative care.[9] Patients receiving palliative care often desire to spend as much time as possible at home while feeling secure.[10] To manage patients in home-based palliative care largely alleviates burdensome symptoms and improves quality of life. This is why home-based palliative care has become increasingly prevalent, especially since the COVID-19 pandemic.[11] Various complex challenges must be taken into account for adult patients in home-based palliative care. Adults in palliative care frequently grapple with long-standing chronic illnesses,[12] multiple concurrent medical conditions,[13] and more intricate psychological needs,[14] all of which can complicate care and treatment planning. Additionally, challenges also exist in care coordination and communication at home can complicate transitions between hospital-based and home-based palliative care, while these transitions, if not managed effectively, can lead to increased healthcare consumption, poor care quality, and threats to patient safety.[15]

The prevalent utilization of electronic symptom monitoring provides more opportunities for the practice of home-based palliative care.[16,17] However, the effectiveness of electronic symptom monitoring in home-based palliative care has not been comprehensively evaluated. While there are comprehensive studies that mention electronic symptom monitoring in home-based palliative care, they do not specifically focus on or provide a detailed description of it.[17]

Therefore, the objective of this systematic review is to: (1) delineate the essential features of the existing studies and electronic symptom monitoring systems; (2) evaluate the feasibility, effectiveness, and limitations of electronic symptom monitoring in home-based palliative care; and (3) appraise the quality of evidence, pinpoint evidence gaps, and suggest implications for future relevant practice and research.

Methods

The authors opted for a systematic review, meta-analysis, and narrative synthesis methodology to examine the evidence on the use of electronic symptom monitoring in home-based palliative care. This research approach was

chosen to systematically search, evaluate, and synthesize relevant research evidence in this area.

This systematic review was conducted according to the Cochrane Handbook for Systematic Reviews of Interventions[18] and reported as per the Preferred Reporting Items for Systematic Reviews and Meta-Analyses reporting guideline 2020 (PRISMA 2020).[19] More details can be found in the Supplemental File 2.

Protocol and registration

The review protocol was pre-registered in PROSPERO (CRD42023457977).

Search strategy

We searched the Cochrane Central Register of Controlled Trials (CENTRAL), Embase (OvidSP), and MEDLINE (OvidSP). Keywords related to electronic systems, symptom monitoring/assessment, patient reported outcomes and palliative care were included in the search strategy (Supplemental File 3). The final search was conducted on September 8th, 2023. A preliminary search was conducted using each of the four databases to identify a list of relevant search terms. The databases were then systematically searched using a combination of free-text terms or Mesh terms. We used search terms related to home-based palliative care, electronic symptom monitoring, and patient-reported outcomes. We applied no restrictions in language and publication date. Subsequently, all search results were imported into EndNote 20 (Thomson Reuters, Canada) for data storage.

Eligibility criteria

Eligibility criteria are shown in Table 1.

Study selection

Two authors (SM and LL) screened titles and abstracts of studies retrieved in the search. The full texts of studies potentially relevant to this review were downloaded for detailed assessment. Appropriateness for inclusion of the studies was assessed by two authors (SM and LL) independently. In case of disagreement, a consensus was reached through discussion with the arbitrator (YCao).

Data extraction

Two authors (SM and LL) conducted the data extraction process independently using standardized data extraction forms and cross-checked their findings. In the event of any discrepancies, a consensus was reached through discussion with the arbitrator (YCao). Subsequently, the data obtained from the extraction forms were consolidated into a unified format. The following data were extracted: name of the first author, year of publication, country in which the study was performed, study design, population type, participants' age, sample size, setting, intervention/control administrated, characteristics of electronic symptom monitoring systems, and outcomes.

Characteristics of electronic symptom monitoring systems included:

- Whether the patient's basic characteristics are displayed on the interface?—Yes or no.
- Whether the system is integrated with electronic health records?—Yes or no.
- Which scale or index is used to score or grade the symptom?
- When could patients report symptoms?—at any time (real-time), and/or at a specific time as the system requires (time-based).
- When will the system remind patients of symptom reporting?
- How will the system remind patients of symptom reporting?
- Who can access the changing trend of symptom data over time?—clinicians, patients, and/or other patients with permission.
- When can personnel access the changing trend of symptom data over time?—Real-time and/or time-based.
- Which form is adopted to present over-time symptom data?—Line chart, bar chart, or other forms.
- What are the criteria or threshold scores for triggering alerts or notifications based on patient-reported outcomes?
- How to alert the patients and/or healthcare team when patient-reported outcomes exceed the predefined threshold?
- How to manage the worsening symptoms after receiving the alert?
- How to deliver educational materials to patients via the system?
- How can patients communicate with each other or with personnel of the healthcare team?

The following 11 categories of outcomes were extracted:

- Patient engagement: defined as the desire and capability to choose to utilize electronic symptom monitoring service actively[20]; measured by (1) number of completions (the number of times participants complete the symptom reporting via the electronic symptom monitoring system), (2) number of accesses (the number of times participants access the electronic symptom monitoring system), and (3) completion rate (calculated as the number of completions divided by the expected accesses).

Table 1. Inclusion/exclusion criteria.

	Inclusion criteria	Exclusion criteria
Population	• Aged ⩾18 years • In any home-based palliative care trajectory, regardless of diagnosis	• Patients unable to access to the World Wide Web, a smartphone app, or an automated telephone interface due to any reason • Patients unwilling to participate in the study of electronic symptom monitoring
Intervention	• Electronic symptom monitoring systems provide real-time monitoring that enables patients to submit PROs at any time	• Wearable or implantable sensors collecting vital signs • Paper-based symptom monitoring in hospitals or clinics • Symptom recording or reporting without monitoring by healthcare personnel
Comparison	• Any comparator or no comparator	• Not applicable
Outcome	• Patient engagement • Quality of life • Physical functioning • Emotional functioning/well-being • Symptom scores • Survival • Hospital admission • Emergency visit • Length of hospital stay • Cost effectiveness • Adverse events	• Not applicable
Study	• English languages • Original studies including randomized/ quasi-randomized controlled trials, non-randomized controlled trials, observational studies (cohort, cross-sectional, and case-control studies), and feasibility/pilot studies	• Non-English paper • Reviews, conference abstracts, editorials, comments, and letters

- Quality of life: defined as an individual's subjective perception of their overall position in life, taking into account the cultural and value systems within which they exist, which also encompasses their goals, expectations, standards, and concerns[21]; measured by any validated tools/scales.
- Physical functioning: defined as the ability to perform basic and instrumental activities of daily living[22]; measured by any validated tools/scales.
- Emotional functioning/well-being: defined as any report of the status of a participant's ability to manage and express emotions effectively, contributing to overall psychological health[22]; measured by any validated tools/scales.
- Symptom scores: defined as any report of a numerical assessment used to quantify the severity or frequency of symptoms experienced by a participant of a specific disease[23]; measured by any validated tools/scales.
- Survival: defined and measured by various metrics including the time from the start of the intervention to death from any cause or a specific disease, as well as the duration that participants live with the disease without it deteriorating. Additionally, survival can be measured based on the proportion of participants who die during the follow-up period.[24]
- Hospital admission: defined and measured as proportion of participants admitted to hospital for any reason.[25]
- Emergency visit: defined and measured as proportion of participants visiting the emergency department at least once.[26]
- Length of hospital stay: defined and measured as days patients revisit hospital after having home-based palliative care.[27]
- Cost effectiveness: defined and measured as electronic symptom monitoring's effects on medical costs during palliative care.[28]
- Adverse events: defined and measured as any adverse events related to the electronic symptom monitoring application.[25]

Evidence synthesis

The design, setting, participants, follow-up procedures, and details about the intervention and control groups of

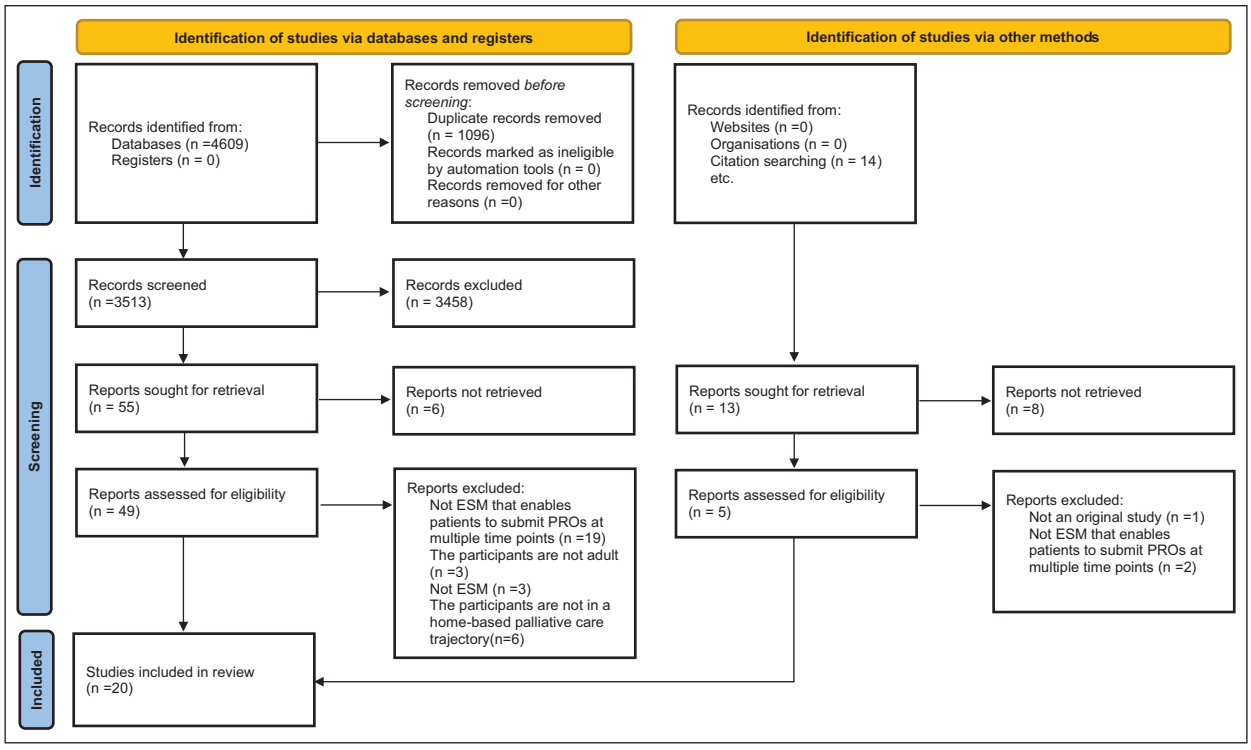

Figure 1. The PRISMA 2020 flow diagram.

included studies were summarized. To streamline the summarization process, a Microsoft Excel spreadsheet was utilized, which employed a standardized data extraction form in alignment with the initial data extraction procedures. For two-arm or pre-post comparison, the risk ratio (RR, indicating the ratio of the risks for an event for the intervention group to the risks for the control group) and 95% confidence interval (95%CI) were reported or calculated for dichotomous variables, whereas mean difference and 95%CI was reported or calculated for continuous variables.

Meta-analyses were performed on randomized controlled trials reporting outcome measures of survival and hospital admission. Statistical heterogeneity was assessed using the I^2 statistic. Considering the variation in disease type and age among the patient populations, the meta-analyses were performed using the DerSimonian and Laird random effects models in RevMan 5.4.[29]

Regarding the remaining outcomes in randomized controlled trials and nonrandomized studies on interventions, there was significant heterogeneity in terms of the population and measuring methodology, or only a significantly limited number of results within the same domain. As a result, these outcomes were deemed unsuitable for meta-analysis. Instead, they were synthesized using the core narrative methods outlined in the Cochrane Handbook for Systematic Reviews of Interventions,[30] and reported following the SWiM (Synthesis Without Meta-analysis) reporting guideline[31] (Supplemental File 4).

Quality assessment

We used version 2 of the Cochrane risk-of-bias tool for randomized trials (RoB2)[32] to assess the quality of randomized controlled trials. For nonrandomized studies on interventions, the Risk Of Bias In Non-randomized Studies of Interventions (ROBINS-I) tool[33] was used. The quality assessment was independently undertaken by two authors (SM, LL). Any disagreement was discussed with the third author (YCao).

Results

Study selection

Figure 1 illustrates the flow diagram for the search strategy. The initial searches retrieved a total of 4609 articles, and 1096 studies were removed due to duplication. After analysis of titles and abstracts, another 3458 articles were excluded, and 49 studies were selected for full-text reading. Another 2 studies were identified through citation searching. Following full-text reading, 31 articles were excluded (Supplemental File 5). Finally, 20 articles were included in the present systematic review.

Study characteristics

A total of twenty studies that met the inclusion criteria were identified and conducted between 2006 and 2023 (Table 2). Among these, four were randomized controlled

Table 2. Characteristics of included studies.

Study	Country	Study design	Electronic symptom monitoring system	Control	Participants	Sample size (total/intervention)	Gender (F/M)	Age (mean, range)	Follow up duration
Maudlin, 2006	America	Feasibility study	Health Hero	–	1. Veterans 2. With chronic end-stage illnesses including dementia, emphysema, heart failure, and cancer	100/100	0/100	NR	6 months
Maguire, 2015	UK	Feasibility study	Advanced Symptom Management System	–	1. >18 years 2. With lung cancer receiving a course of thoracic radiotherapy	16/16	11/5	63.6, 42–85	12 months
McCall, 2008	UK	Feasibility study	Advanced Symptom Management System	–	1. >18 years 2. With advanced cancer	21/16	7/14	64, 40–87	30 days
Maguire, 2021	UK	Randomized controlled trial	Advanced Symptom Management System	Usual care	1. >18 years 2. Breast cancer, colorectal cancer, Hodgkin's, or non-Hodgkin's lymphoma 3. ⩾3 cycles of chemo or first-time in 5 years 4. Physically/psychologically fit, local language proficiency	829/415	678/151	52.4	6 cycles
Gustafson, 2017	America	Randomized controlled trial	Comprehensive Health Enhancement Support System and Clinician Report	Comprehensive Health Enhancement Support System only	1. >18 years 2. Breast cancer: Recurrent or metastatic; Prostate cancer: Hormone-refractory or metastatic; Lung cancer: Stage IIIA, IIIB, or IV disease	217/107	121/96	63	12 months
Bonsignore, 2018	America	Feasibility study	TapCloud	–	1. ⩾18 years of age 2. One or more life-limiting illnesses 3. Lived at home in one of the seven rural WNC counties that Four Seasons serves 4. Wireless home or 3G/4G capabilities	101/101	60/41	72, 71–90	12 months
Nemecek, 2019	Austria	Clinical controlled trial	VSee	Usual care	1. 18–75 years 2. With advanced cancer, patients with an ECOG performance status of 0 or 1, as well as patients with an ECOG of 2 without cognitive impairment	15/8	NR	48.5	6 months
Helleman, 2020	Netherlands	Feasibility study	Amyotrophic Lateral Sclerosis Home-monitoring and Coaching	–	1. >18 years 2. With amyotrophic lateral sclerosis	23/23	6/17	63.2	6 months
Pavic, 2020	Switzerland	Feasibility study	Active Monitoring	–	1. >18 years 2. Estimated life expectancy >8 weeks to <12 months 3. ECOG performance status ⩽2 or Karnofsky Performance Status ⩾50% 4. No significant cognitive impairment and proficient in the German language	31/31	9/22	64, 53–71	18 months

(Continued)

Table 2. (Continued)

Study	Country	Study design	Electronic symptom monitoring system	Control	Participants	Sample size (total/ intervention)	Gender (F/M)	Age (mean, range)	Follow up duration
Bhargava, 2021	Canada	Feasibility study	Remote Symptom Management System—Relieving Symptoms of Cancer and Treatment side effects in the Community	–	1. >18 years 2. With metastatic cancer 3. Alert and oriented 4. Able to understand and communicate in English or have a family member who could 5. Able to access a desktop, laptop, smartphone, or tablet with internet access	13/13	NR	63	2 months
Castillo Padros, 2023	Spanish	Feasibility study	HumanITcare	–	1. >18 years; 2. Advanced pathologies that motivated inclusion in palliative care	60	36/24	72	30 days
Schuler, 2023	Australia	Feasibility study	Garmin Connect and mEMA	–	1. >18 years 2. Recruited from an outpatient palliative care clinic for people with cancer	15	12/3	59, 50–66	33 days
Lee, 2023	Korea	Randomized controlled trial	Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events app	Usual care	1. >18 years 2. Diagnosed with breast, lung, head and neck, esophageal, or gynecologic cancer 3. Scheduled to receive chemotherapy and/or radiation therapy and who had their smartphone	213/142	138/84	55.9	8 weeks
Cornetta, 2023	Kenya	Feasibility study	Telehospice	–	1. >18 years old 2. Moi University Teaching and Referral Hospital patients who carried a suspected or biopsy-documented metastatic or locally advanced cancer 3. Had a Palliative Care Performance Status of 30–60	30/30	8/22	20–93	8 weeks
Zylla, 2020	America	Feasibility study	Epic MyChart	–	1. >18 years 2. Within 3 months after a diagnosis of stage IV non-hematologic cancers (lung, colorectal, prostate, pancreas, head and neck, esophageal and stomach, breast, ovarian, cervical, endometrial, liver/bile duct, and kidney	80/80	53/27	61	12 weeks
Bakitas, 2020	America	Randomized controlled trial	Enhancing Activation and Knowledge in Chronic Heart Failure—Palliative Care	Usual care	1. ⩾50 yeears 2. English-speaking 3. With clinician-documented NYHA class III or IV heart failure or American College of Cardiology stage C or D heart failure	415/208	194/221	63.8	32 weeks

(Continued)

Table 2. (Continued)

Study	Country	Study design	Electronic symptom monitoring system	Control	Participants	Sample size (total/intervention)	Gender (F/M)	Age (mean, range)	Follow up duration
Wujcik, 2022	America	Feasibility study	Carevive	–	1. >18 years 2. Diagnosis of breast, lung, ovarian cancers, multiple myeloma, or acute myeloid leukemia 3. Planned chemotherapy for a minimum of 12 weeks 4. Access to a smartphone, tablet, or computer	282/282	241/41	58.96	12 weeks
Adam, 2021	UK	Feasibility study	Can-Pain	–	1. >18 years 2. Both with bony metastases on opioids and gabapentin	2/2	1/1	55-73	4 weeks
Besse, 2016	Netherlands	Feasibility study	Interactive Voice Response and Short Message Service	–	1. >18 years 2. With any kind of cancer together with cancer-related pain 3. Access to a mobile phone, living at home, and provision of written informed consent	13/13	3/10	58, 27–75	4 weeks
Hochstenbach, 2016	Netherlands	Feasibility study	A web application	–	1. Diagnosis of cancer 2. Under (palliative) anti-tumor treatment in a day clinic or outpatient clinic, or having no treatment options available anymore 3. Moderate to severe cancer (treatment-related) pain ⩾4 (Numeric Rating Scale 0–10) for >2 weeks 4. Living at home	11/11	6/5	53	4 weeks

NR: not reported; ECOG: Eastern Cooperative Oncology Group.
The total number encompasses the participant count in both the intervention and control groups for comparative studies. In feasibility studies, the total number corresponds to the participant count only in the intervention group.

trails, while the remaining sixteen were nonrandomized studies on interventions. Nine studies originated from Europe, with three from the Netherlands, five from the UK, and one each from Switzerland and Spain. Additionally, one study each came from Australia, Canada, and Kenya. All studies were conducted in patients' homes, and a total of 2487 patients were included in the analysis. Study sizes varied, with the number of patients ranging from 2 to 829, all of whom received palliative care at home using an electronic symptom monitoring system. Participant characteristics were inconsistently reported across the studies, but among those that did report, a majority of patients had a cancer diagnosis. Moreover, most studies specifically enrolled elderly patients, with participant ages ranging from 20 to 93 years. Each study reported at least one main outcome, with two studies reporting the highest number of seven main outcomes. In total, 18 electronic symptom monitoring systems were included in this study, and their characteristics were summarized in Supplemental File 6.

Risk of bias assessment

Regarding Randomized controlled trials, the RoB2 assessments showed that some concerns existed regarding the overall risk of bias in four of the included studies. All the four studies[25,34–36] had unclear or high risk of bias due to deviations from the intended intervention, and half of them failed to report some outcome data (Figure 2(a)). Moving on to nonrandomized studies on interventions, the use of ROBINS-I tools revealed that most of the included studies (11 out of 16) had serious issues in terms of overall assessments. While some studies had achieved low or moderate deviations from the intended interventions, most of them (10 out of 16) had serious bias due to confounding, while the remaining studies had moderate bias, ultimately downgrading the overall assessment scores. In terms of participant selection and missing data, most of the studies had moderate concerns, but two studies presented serious issues related to missing data (Figure 2(b)). In general, the risk of bias across all studies was either unclear or high. Consequently, it is advisable to interpret the findings cautiously.

Main findings of included studies

The overall outcome reporting schema of included studies was presented in Table 3.

Patient engagement. Sixteen studies reported patient engagement outcomes. The measurements of patient engagement mainly focused on the number of completions for accessing the system. The most frequently reported measure of patient engagement was the completion rate, which was mentioned in 13 out of 16 studies (13/16).[25,26,28,35,37–44]. Additionally, two studies reported the number of completions[45,46] and one study reported the number of accesses.[47] The completion rates in the electronic symptom monitoring group varied between 44% and 100%. Cornetta et al.[40] assessed Telehospice, an electronic symptom monitoring system that evaluates patient health status and symptoms through phone calls, facilitating remote patient care and timely intervention and providing tailored advice and contact information of medical navigators, even reported a 100% participation rate in weekly follow-up calls. However, only a few participants made full use of the electronic symptom monitoring system. On the other hand, Zylla et al.[41] reported that although most patients agreed that the electronic survey was straightforward and helpful in addressing their symptoms, the response rates via Epic MyChart (an electronic system combining medical record and PROs monitoring) were only 46%. Bhargava et al. reported that some nonadherence rates were related to factors unrelated to the electronic symptom monitoring system itself, but rather to the health of the patient.

Patient engagement was also evaluated using interviews or structured questionnaires. Eight studies[25,27,39,40,41,44,47,48] reported that most patients were satisfied with the electronic symptom monitoring systems and found them comfortable and easy to use. Three studies[26,28,37] reported that most patients would like to use electronic symptom monitoring again or recommend it to other patients. However, Helleman et al.[37] (evaluating a system to navigate symptom data with alerts to health professionals for severe symptoms called Amyotrophic Lateral Sclerosis Home-monitoring and Coaching) also reported that 13% of participants found the use of electronic symptom monitoring burdensome. In summary, patient engagement varied for different electronic symptom monitoring systems, patients' non-adherence is caused by their health condition or the burden caused by filling out the questionnaire through the electronic symptom monitoring systems.

Quality of life. Five studies[25,28] assessed different aspects of quality of life. Two pilot studies did not find evident improvement by electronic symptom monitoring. Nemecek et al.[18] found no significant difference in the quality of life evaluated by FAMCARE (Family Satisfaction with End-of-Life Care) and QLQ-C15 (EORTC Quality of Life Questionnaire-Core 15) scores between the control and the intervention group. Besse et al.[35] reported a non-significant increase in overall quality of life measured by the EORTC QLQ C30 (EORTC Quality of Life Questionnaire-Core 30) scale. However, all three randomized controlled trials showed increased quality of life compared to control. Lee et al.[35] reported that the intervention group was more likely to have a good quality of life compared to the control group (35.9% vs 33.8%) as measured by EORTC Quality of Life Questionnaire Core 30. Maguire et al.[25] (evaluating a system navigating symptom

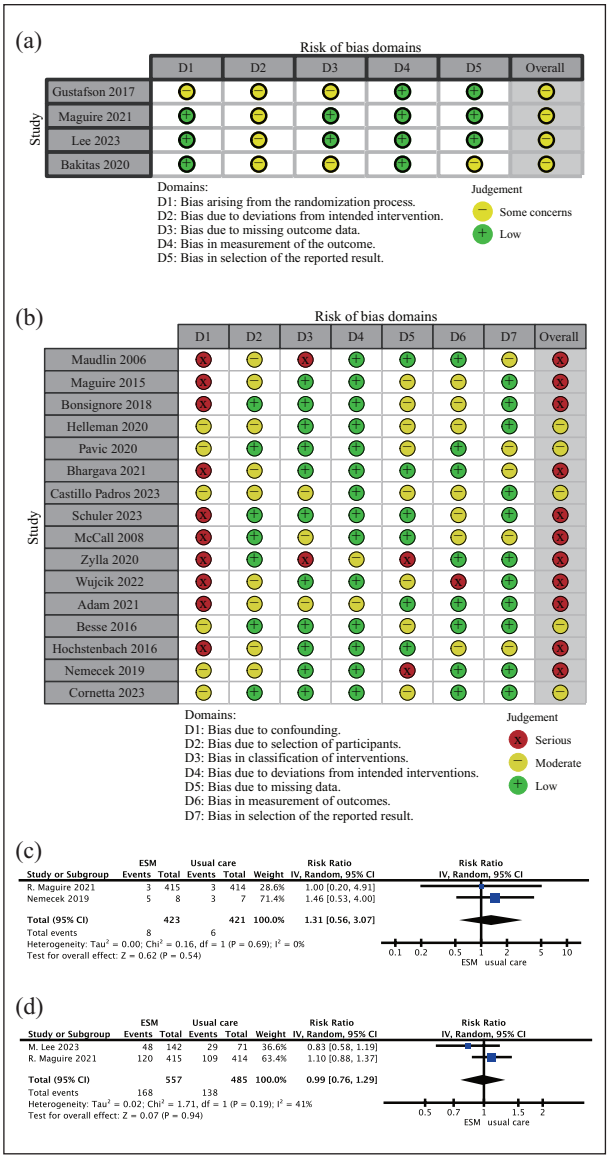

Figure 2. Forest plots of the survival and hospital admission outcomes and quality assessment of included studies: (a) quality assessment of the randomized clinical trials according to RoB2 tool, (b) quality assessment of the nonrandomized studies of interventions according to ROBINS-I tool, (c) forest plot of survival outcomes for ESM versus usual care, and (d) forest plot of hospital admission outcomes for ESM versus usual care.

data with alerts to health professionals for severe symptoms) reported that FACT-G (Functional Assessment of Cancer Therapy-General) scores were higher in the intervention group than in the control group (MD = 4.06, 95%CI 2.65 to 5.46, $p < 0.05$). Bakitas et al.[36] indicated improvements in quality of life scores for palliative therapy and heart failure participants evaluated by Functional Assessment of Chronic Illness Therapy—Palliative Care 14 score. In summary, results from randomized controlled trials consistently supported that electronic symptom monitoring could enhance patients' quality of life.

Physical functioning. Two studies[25,45] reported outcomes related to physical functioning. In the pilot study by Maguire et al.,[45] no statistical significance was observed in major physical functioning domains, including fatigue, drowsiness, and appetite. However, a recent trial by the same research group[25] showed electronic symptom monitoring improved the physical functioning domains, compared with the control group (allocated to standard care). They also found that support needs measured by Supportive Care Needs Survey Short-Form 34 were lower in most domains, including sexuality needs ($p < 0.05$), patient care and support needs ($p < 0.05$) and physical and daily living needs ($p < 0.05$). Overall, though insignificant in the pilot study, the high-quality evidence supported the improvement of physical functioning by electronic symptom monitoring.

Emotional functioning/well-being. Seven studies reported outcomes related to emotional functioning and well-being, specifically focusing on anxiety and depression. Three studies[28,47] reported significant decrease in anxiety and depression for the electronic symptom monitoring group, while another three did not. The pilot study by Maguire et al.[45] found that patients reported moderate levels of anxiety both at baseline and follow-up. A single-arm study conducted in Kenya by Cornetta et al[40] reported that worry and feelings of not being at peace were at moderate severity when using electronic symptom monitoring. Schuler et al.[39] using an electronic symptom monitoring system to track health and fitness and collect emotional functioning/well-being data, found that 17% of patients experienced moderate or severe distress. However, the randomized controlled trial by Maguire et al.[25] noted a slight improvement in mean scores for the "positive attitude" and "making decisions" subscales following electronic symptom monitoring use, along with lower scores on the anxiety scale compared to the control group. Supported by 3/6 pilot studies and the only one randomized trial, electronic symptom monitoring could enhance emotional functioning/well-being, but the effect may be context-dependent.

Symptom scores. Seven studies reported symptom scores. A feasibility study by Schuler et al.[39] reported that patients' mean self-reported Integrated Palliative Outcome Scale score for symptom burden was 17.5 out of 56. Cornneta et al.[40] reported that the pain scores generally improved but were still moderately high throughout the observation. Besse et al.[48] reported that in a 4-week study, the mean NRS pain score decreased nonsignificantly from 4.78 to 3.33 ($p = 0.07$). EORTC Quality of Life Questionnaire Core 30 pain subscale significantly decreased from 56 to 35 ($p = 0.047$). Gustafson et al.[40] found no significant changes in symptom scores. However, three controlled studies[25,35,47] reported improvement in symptom scores. Bonsignore et al.[47] reported that 82% of participants showed improvement in symptoms (measured by a reduction $\geqslant$1 point on

Table 3. Outcome reporting schema of included studies.

Study	Patient engagement	Quality of life	Physical functioning	Emotional functioning/ Well-being	Symptom scores	Survival	Hospital admission	Length of hospital stay	Emergency visit	Cost-effectiveness	Adverse event
Maudlin, 2006	×	×	×	×	×	×	√	√	√	√	×
Maguire, 2015	×	×	×	√	×	×	×	×	×	×	×
McCall, 2008	×	×	×	×	×	√	×	×	×	×	×
Maguire, 2021	√	√	√	√	√	√	√	×	×	×	√
Gustafson, 2017	√	×	×	×	√	×	×	×	×	×	×
Bonsignore, 2018	√	×	×	√	√	√	×	×	×	×	×
Nemecek, 2019	√	√	×	√	×	√	√	×	×	√	×
Helleman, 2020	√	×	×	×	×	√	×	×	×	×	×
Pavic, 2020	√	×	×	×	×	×	×	×	√	×	×
Bhargava, 2021	√	×	×	×	×	√	√	×	√	√	×
Castillo Padros, 2023	√	×	×	×	×	√	×	×	×	×	×
Schuler, 2023	√	×	×	√	√	×	×	×	×	×	×
Lee, 2023	√	√	×	×	√	×	√	×	√	×	×
Cornetta, 2023	√	×	×	√	√	√	√	×	×	×	×
Zylla, 2020	√	×	×	×	×	×	×	×	×	×	×
Bakitas, 2020	√	√	×	√	×	×	×	√	√	√	×
Wujcik, 2022	√	×	×	×	×	×	×	×	×	×	×
Adam, 2021	√	×	×	×	×	×	×	×	×	×	×
Besse, 2016	×	√	×	×	√	√	×	×	×	×	×
Hochstenbach, 2016	√	×	×	×	×	×	×	×	×	×	×

the Edmonton Symptom Assessment System with a total score of 10) using TapCloud (an app for symptom tracking and communication with healthcare providers) by the second or third visit. Maguire et al.[25] reported that Multidimensional Symptom Assessment in Palliative Care indicated a significant reduction in the intervention group (utilizing Advanced Symptom Management System) for global distress index (MD = −0.21, 95%CI −0.27 to −0.16, $p < 0.05$), psychological symptoms(MD = −0.16, 95%CI −0.23 to −0.10, $p < 0.05$), and physical symptoms (MD = −0.21, 95%CI −0.26 to −0.17, $p < 0.05$). They also found that 81.8% of patients using electronic symptom monitoring showed improvement in pain. Lee et al.[35] found patients who use electronic symptom monitoring for home-based palliative care have less symptom burden. Collectively, these findings from high-quality evidence consistently supported that electronic symptom monitoring could effectively reduce symptom scores assessed by diverse scales.

Survival. Nine studies reported survival outcomes. Most studies[37,38,40,44,47,48,49] only reported deaths during the intervention, which precluded the analysis on the effects of electronic symptom monitoring. Our synthesis of two randomized controlled trials[16,25] revealed no statistical difference (RR = 1.31, 95%CI 0.56 to 3.07, $p > 0.05$) in deaths between the electronic symptom monitoring used in home-based palliative care and usual care (Figure 2(c)).

Hospital admission. Six studies reported outcomes related to hospital admission. Three single-armed studies[27,40,49] reported hospital admission rates ranging from 30.7% to 66%. A non-randomized controlled clinical trial[28] found no significant difference in hospital admission between groups (87.5% for electronic symptom monitoring versus 85.7% for usual care). The meta-analysis synthesizing two randomized controlled trials[27,35] reported fewer hospital admissions in electronic symptom monitoring group than usual care (RR = 0.99, 95%CI 0.76 to 1.29, $p > 0.05$) (Figure 2(d)). To summarize, no evident effect of electronic symptom monitoring was found on hospital admissions.

Length of hospital stay. Two studies reported the length of hospital stay. Maudlin et al.[27] reported that 77% of patients using electronic symptom monitoring experienced a reduced number of bed days compared to the mean length of usual care. However, the randomized controlled trial by Bakitas et al.[36] evaluating the Enhancing Activation and Knowledge in Chronic Heart Failure—Palliative Care (an innovative program aimed at improving patient activation and knowledge in individuals with chronic heart failure receiving palliative care) reported no relevant between-group differences in hospital stay ($p > 0.05$). Hence, we could not conclude that electronic symptom monitoring could reduce the length of hospital stay.

Emergency visit. Five studies reported outcomes related to emergency visits. In the single-arm study, Pavic et al.[26] reported that 36.7% of patients had an emergency visit, while Bhargava et al.[49] reported no emergency visits. Two feasibility study reported a reduction in emergency visits. Maudlin et al.[27] reported a 19% reduction in emergency department visits over 6 months, while Lee et al.[35] reported a similar trend in ER visits (19.7% vs 22.5%). However, the randomized controlled trial by Bakitas et al.[36] reported no relevant between-group differences in emergency visit ($p > 0.05$). Consequently, we could not conclude that electronic symptom monitoring could reduce the emergency visit.

Cost effectiveness. Four studies reported the cost effectiveness outcomes, primarily comprising admissions and emergency department costs. Three of them[27,28,49] reported a reduction of cost by using the electronic symptom monitoring system, while Bakitas et al.[36] reported that no intergroup difference was observed in resource use. All these results demonstrate that using electronic symptom monitoring will not increase the health economic burden. reported a reduction of cost by using the electronic symptom monitoring system, while Bakitas et al.[36] reported that no intergroup difference was observed in resource use. All these results demonstrate that using electronic symptom monitoring will not increase the health economic burden.

Adverse events. Only one study, Maguire et al.[25] reported that neutropenic events were higher in the intervention group (125/414) than in the control group (71/415). However, it was unclear whether this adverse event was associated with using an electronic symptom system.

Discussion

Summary of main findings

This systematic review synthesizes evidence from 20 studies and provides a comprehensive summary of the use of electronic symptom monitoring in home-based palliative care. Most patients have a positive attitude to engagement in electronic symptom monitoring. Electronic symptom monitoring systems show the potential to improve patient's quality of life, physical functioning, emotional functioning/well-being, and symptom scores without increasing costs. Nevertheless, definitive conclusions regarding the impact of electronic symptom monitoring on survival, hospital admissions, length of hospital stays, emergency visits, and adverse events were precluded due to substantial heterogeneity or inadequate statistical power.

Overall completeness and applicability of evidence

Improvement of patient's quality of life, physical functioning, emotional well-being, and symptom scores has validated the effectiveness of electronic symptom monitoring in home-based palliative care. This remote intervention has the potential to directly impact the psychological status of patients. Prior research indicates that more than one-third of patients found psycho-existential symptoms distressing and burdensome; for example, 35.8% experienced feelings of hopelessness, 26.9% expressed a sense of pointlessness and loss of life's value, and 17.0% harbored a desire to hasten death.[50] Despite this, the current provision of psychological services in palliative care is likely insufficient.[51] Electronic symptom monitoring can alleviate their fear of burdening others by involving patients in reporting and managing their symptoms.[52] Additionally, the communication platform allows patients to discuss concerns about loved ones, symptom management, fear of isolation, and the approaching end of life.[53] Furthermore, patients demonstrated a greater willingness to seek psychological support through a remote digital system compared to face-to-face interactions.[54]

When interpreting its applicability, it is essential to note that certain studies have indicated no significant enhancements in patient-reported outcomes. Besse et al.[48] reported a nonsignificant rise in quality of life as measured by the EORTC Quality of Life Questionnaire-Core 30. However, we did not incorporate these findings into the primary conclusion due to the recruitment of only a single arm consisting of 13 patients in the feasibility study. Additionally, we observed that some patients found the electronic symptom monitoring system burdensome. These adverse findings serve as a reminder that electronic monitoring systems may not be suitable or beneficial for all patients. While acknowledging the advantages of electronic symptom monitoring using evidence-based approaches, clinicians should base their decision to initiate or continue using such systems on the perception of individual patients.

Furthermore, there are ongoing concerns regarding its practicality in real-world scenarios. The majority of studies have been conducted in high-income nations, with minimal focus on the medical expenses related to electronic symptom monitoring. The sole study from a low-income country[38] found that worry and feelings of unease persisted at a moderate level during electronic symptom monitoring. The preexisting anxiety among patients in this study may be linked to limited medical resources in Kenya, and electronic symptom monitoring alone may not adequately address their symptoms and worries without a robust healthcare infrastructure. Moreover, while four studies indicated that electronic symptom monitoring would not add to the economic burden on healthcare, none of them considered the direct costs of implementing the monitoring system. Although patients could use the system in research settings, expenses related to software development, maintenance, utilization, and additional staffing could pose a financial strain on patients and healthcare systems in real-world scenarios. Failure to assess the impacts across various populations and healthcare systems could potentially lead to inequities in health outcomes with the digital implementation of electronic symptom monitoring.[55]

Despite the potential benefits of electronic symptom monitoring in improving patient-reported outcomes, there were no clear advantages observed in terms of survival or other disease progression-related outcomes. Nonetheless, these findings should not discourage the implementation of electronic symptom monitoring. Given the complex and varied disease presentations in palliative care patients, it is understandable that significant improvements in these outcomes may not be achieved through electronic symptom monitoring. Additionally, the interpretation of increased hospital admissions or emergency visits is challenging, as early detection of aggregated or progressive symptoms through electronic symptom monitoring could lead to either an increase or decrease in hospital admissions or emergency visits, depending on whether symptoms can be managed without professional medical intervention.

Quality of evidence

All the randomized controlled trials included in our analysis were judged to have an overall unclear risk of bias due to potential deviations from the intended intervention. Blinding is commonly considered a method to mitigate the Hawthorne effect in clinical trials, which refers to a change in behavior in response to observation and assessment.[56] If unblinding in electronic symptom monitoring were to lead to a Hawthorne effect prompting patients to make greater efforts to improve their quality of life, the objective of palliative care would be further advanced. Therefore, the impact of the lack of blinding of participants may be minimal in studies relating to home-based palliative care. Additionally, given the complex disease conditions of palliative care patients, it is expected that a significant number of participants may be lost to follow-up. However, such loss to follow-up is likely due to the progression of the disease rather than flaws in the study design. Despite potential limitations, we acknowledge the reliability of the results from these randomized controlled trials, although a reduction in statistical power may occur due to the smaller sample size. Overall, we recognize the valuable supportive evidence provided by these randomized controlled trials in the context of this review.

Non-randomized studies, particularly single-arm feasibility studies, may pose a high risk of bias inherent to their

design. Nonetheless, their initial findings can aid in identifying potential trends in conclusions and pinpoint areas for future research.

Strength and limitations

This is the first systematic review to comprehensively evaluate the effect of electronic symptom monitoring on home-based palliative patients. The review focuses on studies reported in English, following an exhaustive search methodology to ensure transparency and replicability. The meticulous screening process identified all relevant English-language studies, enabling the synthesis of available evidence.

While this review aims to draw broad conclusions by synthesizing various studies involving different electronic symptom monitoring systems and patients with life-threatening illnesses in home-based palliative care, it acknowledges limitations. According to limited and contradictory evidence, we could not be more conclusive for our readers about survival, hospital admissions, length of hospital stays, emergency visits, and adverse events. However, as these outcomes are not the primary aim of palliative care, we did not consider that it would alter our overall conclusions. Then, challenges arose from the varied use of indices or scales across studies, impeding the synthesis of outcomes and the performance of a quantitative meta-analysis. To tackle this issue, the study utilized the narrative synthesis method in conjunction with the SWiM reporting guideline to summarize the results and reach the most comprehensive conclusion possible.

Implications for future research

Given the limited number of studies in this emerging field, we propose that future research focus on the following areas. Firstly, there is a need for more high-quality randomized controlled trials or large-scale real-world studies to enhance our understanding of the effectiveness of electronic symptom monitoring systems across short-, medium-, and long-term care durations. Secondly, further investigations should consider patients with severe or life-threatening non-cancer conditions such as end-stage heart failure, liver failure, kidney failure, chronic obstructive pulmonary disease, stroke, dementia, Parkinson's disease, among others. Thirdly, while some studies have emphasized improvements in specific patient-reported outcomes, the significance of the overall quality of life in palliative care has been overlooked. We recommend the use of patient-reported outcome measures such as the EORTC Core Quality of Life Questionnaire and the 36-item Short Form Health Survey for a comprehensive evaluation of patients' overall quality of life.[57]

Implications for future practice

Electronic symptom monitoring systems have the potential to improve patients' quality of life, physical function, and emotional well-being, while also alleviating symptoms. However, further trials are required to draw definitive conclusions. It is advisable to incorporate electronic symptom monitoring systems into home-based palliative care only when they are accessible, feasible, and, most importantly, acceptable to patients. Given the limited, at times inconsistent, and low-certainty evidence available, a cautious interpretation of results and a meticulous implementation of the electronic symptom monitoring system are essential. Especially in situations where the additional benefits of electronic symptom monitoring are uncertain, ensuring patient willingness and satisfaction with its utilization is crucial. The decision whether to adopt the system or not should always prioritize the core principle of palliative care, which is to enhance the quality of life for patients.

Conclusion

Implementing electronic symptom monitoring in home-based palliative care shows promise for addressing medical resource scarcity. This review indicates that electronic symptom monitoring can improve patients-reported outcomes and have the potential to reduce hospital visits and costs, aiding decision-making for patients and caregivers to make patients more comfortable during the palliative care. However, heterogeneity and varied electronic symptom monitoring systems in current studies introduce inconsistencies and hinder comparability. Further, high-quality research in this field is lacking. To bridge this gap, future studies should incorporate standardized follow-up periods or internationally recognized evaluation scales, enhancing comprehension of electronic symptom monitoring benefits in home-based palliative care.

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Author contributions

SM, LL, and CM contributed equally. YCao conceived this study. SM, TW, and YueC were involved in the development of the study question, inclusion/exclusion criteria and data extraction tables. SM, LL, and CM performed the literature search, study selection, data extraction, and quality assessment. SM, LL, CM, and ZJ contributed to the data analysis, and drafted the manuscript. CH, CL, and YCao critically revised the manuscript for significant intellectual content. All authors have reviewed and approved the final manuscript.

Data management and sharing

The data supporting the findings of this study are available within the article and its supplementary materials.

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Supplemental material

Supplemental material for this article is available online.

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