A systematic review of the use of the electronic health record for patient identification, communication, and clinical support in palliative care

Ruth A. Bush[1], **Alexa Pérez**[1], **Tanja Baum**[1], **Caroline Etland**[1,2], and **Cynthia D. Connelly**[1]

[1]Beyster Institute of Nursing Research, Hahn School of Nursing and Health Science, University of San Diego, San Diego, California, USA

[2]Education, Department of Research and Professional Practice, Sharp Chula Vista Medical Center, Sharp Healthcare System San Diego, San Diego, California, USA

Abstract

Objectives: Globally, healthcare systems are using the Electronic Health Record (EHR) and elements of clinical decision support (CDS) to facilitate palliative care (PC). Examination of published results is needed to determine if the EHR is successfully supporting the multidisciplinary nature and complexity of PC by identifying applications, methodology, outcomes, and barriers of active incorporation of the EHR in PC clinical workflow.

Methods: A systematic review using Preferred Reporting Items for Systematic Reviews and Meta-Analyses *(PRISMA)* guidelines. The data sources PubMed, CINAL, EBSCOhost, and Academic Search Premier were used to identify literature published 1999 – 2017 of human subject peer-reviewed articles in English containing original research about the EHR and PC.

Results: The search returned 433 articles, 30 of which met inclusion criteria. Most studies were feasibility studies or retrospective cohort analyses; one study incorporated prospective longitudinal mixed methods. Twenty-three of 30 (77%) were published after 2014. The review identified five major areas in which the EHR is used to support PC. Studies focused on CDS to: identify individuals who could benefit from PC; electronic advanced care planning (ACP) documentation; patient-reported outcome measures (PROMs) such as rapid, real-time pain feedback; to augment EHR PC data capture capabilities; ,and to enhance interdisciplinary communication and care.

Discussion: Beginning in 2015, there was a proliferation of articles about PC and EHRs, suggesting increasing incorporation of and research about the EHR with PC. This review indicates the EHR is underutilized for PC CDS, facilitating PROMs, and capturing ACPs.

INTRODUCTION

The World Health Organization defines palliative care (PC) as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1] PC is patient and family centered medical care, which prevents or treats symptoms and side effects of chronic disease.[2] An interdisciplinary approach is used to treat the multiple co-morbidities, difficult-to-manage symptoms, psychological disruption, and financial challenges of the patients and their families in order to enhance quality of life.[1,3–5]

Globally, PC services are expanding, incorporating better symptom control, care co-ordination, and improved communication among professionals, patients, and families, as well as more efficient resource use.[6–7] Ideally, PC is proactive and begun early in the illness, however, many PC consultations are reactive and occur in the acute care setting, once symptoms become unbearable and the symptom burden overcomes the patient.[1,5,8–10] Oncology patients are more likely to receive PC than non-cancer patients.[3,11] More patients would benefit from PC if screening and assessment were available more broadly and offered earlier.[11]

The electronic health record (EHR) incorporates clinical decision support (CDS) to provide clinicians, staff, patients, and other individuals with knowledge and person-specific information, intelligently filtered or presented at appropriate times, to enhance health and health care.[12] Examples of enhancements include alerts, reminders; clinical guidelines, order sets, data reports, and summaries, document templates, and decision support.[13,14] While using CDS can benefit all healthcare disciplines, CDS is especially helpful for PC patients who are undergoing intensive, interdisciplinary chronic treatment with symptom management, cross-team communication, and patient education with diverse and intensive data capture, including patient reported data if desired.[15,16] Using the EHR to support PC demonstrates the ideal interdisciplinary support envisioned but not always seen with the implementation of the EHR. Additionally, PC requires a transition for the technology framework from supporting disease/illness oriented or restorative care to data and algorithms designed to enhance mainly comfort-oriented care.

To our knowledge, no systematic review specifically focused on the use of EHRs and CDS with PC research has been published. This study's goals were to (1) identify studies describing the active incorporation of the EHR and CDS in PC clinical work flows; (2)

report study findings including patient, caregiver, and healthcare provider feedback; and (3) identify PC facilitation and barriers in current EHRs and related CDS support structure to identify current knowledge gaps and highlight areas for future research.

METHODS

This systematic review used guidelines outlined in Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA).[17] We conducted a comprehensive and broad search of four online databases (National Library of Medicine PubMed access to MEDLINE, CINAHL [Cumulative Index to Nursing and Allied Health Literature], EBSCOhost, and Academic Search Premier) for peer-reviewed literature published between 1999 and September 2017 (see Table 1). In order to capture any pertinent article, we included the terms *electronic decision support*, *electronic medical record*, *electronic health record and eHealth* in combination with the terms *palliative*, *palliative care*, and *palliative medicine*. The selection of articles is outlined in Figure 1.

Citations and abstracts were imported into a Microsoft Access® database. After removing duplicates, two reviewers evaluated abstracts of the 430 unique articles for inclusion using the following criteria: studied humans; peer-reviewed; published journal; printed in English; and included original research and data analysis of PC EHR use. Studies had to have evolved beyond describing a prototype, could not describe future research, and had to involve an aspect of CDS such as using EHR data to support an alert algorithm, creating a PC specific report using a new or revised template designed to capture treatment unique to PC, or other similar support using the EHR. Studies relying on the EHR solely for enhanced lists, not involving PC, or not employing research methodology were not included.

In the second round, two reviewers reviewed the full text of the 191 documents to determine final eligibility based on inclusion criteria. If after a full-text analysis the eligibility of an article was still uncertain, a third reviewer undertook a full text review. Reviewers resolved discrepancies through discussion and documented exclusion reasons. Overall, 30 studies were included.

We created a table including authors, year, genre, study design, setting, participants, description, CDS use type, and results. The preliminary nature of reported results and wide methodologic approach, prevented outcome-level assessment as suggested by the Grading of Recommendations Assessment Development and Evaluation working group.[18]

RESULTS

Five significant themes emerged after compiling, synthesizing, and reviewing the results. The most frequent incorporation of PC CDS in the EHR was to identify individuals who should be screened for PC, using an alert or creating a report, or to support a document template to electronically capture advanced care planning (ACP) directions. Additional themes included using the EHR to capture patient-reported outcomes (PROMs) such as rapid, real-time pain feedback; augmenting the EHR to capture needed PC data elements; and enhancing interdisciplinary communication and care.

Using the EHR to identify individuals for PC—Healthcare systems explored CDS use and related electronic algorithms as a way to alert clinicians and trigger a PC assessment based on patient symptomatology.[2] Highlights of the eight studies (Table 2) exploring CDS to identify individuals for PC include feasibility, symptomatology algorithms development, end-user testing, and data marker refinement to increase patient identification sensitivity. Although CDS-supported alert sensitivity is still maturing, a key finding was that clinicians appreciate the objective CDS structure.[2]

Characteristics of the Studies

Six studies were retrospective or focused on feasibility, while two prospectively identified patients who could benefit from PC in real time. Most studies were conducted in large medical centers after EHR implementation, facilitating incorporation of data from multiple units or even multiple hospitals within their healthcare system. The length of studies ranged from 6 weeks to 9 years of retrospective analysis.[2,21–23] Sample size ranged from 11 patients to 53,124 patients and 225 clinicians. Studies explored the feasibility of automatically capturing patient symptoms (i.e. pain, fatigue, system failure) for EHR decision support.[13,20,21,23,24] In general, using symptomatology-based algorithms supported CDS and resulted in earlier identification of patients for whom discussions about ACP and comfort-oriented care versus life-extending therapy were appropriate.

Two studies examined the healthcare providers' experiences, clinician satisfaction with alerts, and barriers to use.[2,24] Wysham et al.[2] noted more than 75% of the respondents felt PC specialist consultation was underutilized in the intensive care unit (ICU) and using an automated EHR-based trigger was the most frequently preferred means for integrating PC into the ICU setting.

The biggest barriers to CDS were not having the needed or appropriate data and workflow challenges. It is difficult to capture needed qualitative information such as anxiety or family distress in the EHR in a standardized methodology. Clinical billing data may be available but not applicable.[23] Importantly Hua et al.[20] found concrete triggers (e.g. ICU admission) have substantial agreement with subjective triggers (e.g. death expected during ICU stay). Sometimes, the algorithm simply did not work. Hocker et al.[19] found the automated alert to providers of patients with unmet PC needs did not identify many patients who met the criteria. A common physician-identified barrier after using CDS was additional time required to review the results and to discuss an action plan, which clinicians felt diverted focus from other healthcare activities involving a larger percentage of their patients.[21] All studies recommended additional refinement of algorithms and workflows.

Integrating Patient Reporting into the EHR—Conceptually, the EHR's patient portal provides the means for patients to report their condition, needs, and concerns, electronically, in real time to their healthcare providers. These data can be used for reminder alerts and data reports specific to PC and patient care. Patients were most likely to use electronic communication for ACP, to establish a Palliative Care Summaries (PCS), and to report pain.

ACP and PCS

The ACP (and PCS) discussion process allows an individual, family members, and caregivers to communicate wishes and preference for future care and provides an opportunity for patients to have their medical care wishes evolve over time.[27,32] An ACP may include specific treatment preferences for life-sustaining treatment and legal documentation such as physician orders for life sustaining treatment (POLST).[27] Detailed patient preferences for ACP are designed to be accessible to all health professionals and available across platforms, ensuring effective handover of information and improving continuity of care, and help clinicians treat patients according to the patient's wishes.[27,32]

Studies identified were from Australia, the UK, and the USA. Three of the nine studies focused on how many patients had an ACP in place in the EHR.[26,29,32] Two studies assessed whether an ACP was added after a targeted intervention.[25,28] Not having a PCS in place was associated with hospital admission.[31] Another qualitatively assessed providers who had low and high rates of ACP documentation in their EHR.[30] Two studies examined whether clinicians could easily find ACP documentation in the EHR.[27,33] Three studies were in large hospitals; one in a health maintenance organization; one in the Veterans' Administration (VA) Healthcare system, two in a nationalized system, and the remainder in specialty oncology facilities. Participants were 30 oncology patients, a review of 113,309 patient, and 70 physicians.

Among studies of individuals having an ACP on file, 33% of veterans receiving treatment for diabetes and weight management within the outpatient setting had an electronic ACP as part of their health record, although twice as many thought they had documentation on file.[26] In a convenience sample of patients 50 years of age or older attending a primary care clinic, 31% had electronic documentation of a living will or healthcare power of attorney. Those under the age of 70 were more amenable to the concept of completing documentation using an electronic approach than those 70 or older.[25] Of note, both of these studies examined introducing the topic of being ready for future PC among primary care patients attending outpatient clinics rather than among patients likely to need PC in the short term. As part of a targeted intervention study to improve documentation among current PC patients, 9 of 30 participants were willing to complete electronic ACP documentation following a guided discussion. The participants reported that although they thought the documentation was important, the idea of completing it made them anxious.[28] The authors also noted ACP is not routine in the Australian cancer context and remains under explored.

Providers in practices with high and low rates of ACP documentation completed structured interviews to assess factors contributing to documentation. Primary care physicians were more likely to document than specialists.[30] The findings suggest it may be an issue of perceived or real interoperability. Primary care physicians report ACP documentation is accessible while specialist believe interoperability between the hospital and the outpatient EHR systems introduce confusion.[30]

Even when individuals have completed ACPs or other end-of-life (EOL) documentation, this documentation may not be readily found in the EHR. Among a survey of emergency room physicians in a county hospital and in a tertiary academic hospital, although the physicians

thought it was very important to determine if a patient had a POLST or durable power of attorney as part of their record, the physicians lacked the confidence to find or to use ACP EHR documentation. Clinicians' inability to always find the ACP information in the EHR is another barrier to honoring patient preferences.[27] Additionally, emergency department physicians find legal forms such as legal advance directives and specific treatment wishes more helpful than ACP discussion documentation in patient notes. A useful improvement would be to aggregate all ACP information in one place in the EHR, giving it its own.[27] Pre- and post-data analysis of Southern California Kaiser Permanente systems' specialized ACP tab marginally improved physician ability to locate documentation, from 3.5% to 9.6%, depending on medical specialty, after introduction of the tab.[29]

Three electronic PCS studies, a variation of the ACP, were conducted in primary care practices in the UK, directing the use of electronic PCS to ensure end of life wishes were recorded and available for effective information transfer among professionals, especially when patients are seen by a non-regular clinician outside normal hours.[32,33] The studies used qualitative, mixed methods, and retrospective methodology involving 22 health providers and 1229 patients. An evaluation to guide redesign of the PCS in Leeds, UK, found just over 25% of the deaths related to cancer, circulatory, and respiratory disease during the study period had an ACP in place; the majority were put in place about a week before death rather than the desired 12 months before death.[32] Another study found 36% of those presenting to the emergency department had the documentation on file.[31] When surveying clinicians, Hall *et al.*[33] found clinicians thought the PCS was a good idea, but they were not completing the summaries because of time barriers and the lack of computer technology skills.

Patient-Reported Outcomes

Four studies addressed PROMs-employed qualitative, mixed methods, feasibility, and retrospective analysis methodology. Patient samples ranged from 107 to 5837. All studies took place within large healthcare systems, including one study in the VA Healthcare System in the USA. Romaro et al.[37] reported an innovative study in which patient-reported data, including current symptoms, were incorporated in the EHR and could be used by providers for clinical symptom management and EOL decision making. The patients were randomized to standard of care versus patient reporting and those receiving standard of care were more likely to be in the ICU in the last 6 months of life, died in hospital or ICU, and were not enrolled in hospice.

Incorporated reporting varied. A retrospective analysis of patient-reported place of death preference, using a question embedded in the intake form, demonstrated those who requested a home death were more likely to die at home.[36] Two studies examined patient-reporting current symptoms using the US National Institutes of Health Patient Reported Outcomes Information System (PROMIS) on computer tablets, which fed directly into the EHR. One study had 472 patients, the other 632. Both were conducted during 18-month period at large academic hospitals. In one study, patients completed a mean of 4.2 assessments with clinical assistance. In the other study, which sent an electronic message via

the patient portal to initiate assessment, participants completed a mean of 2.3 assessment and 60% of participants never completed a full assessment.

Enhancing the EHR for PC

The fourth area of investigation examined existing EHR enhancements designed to support PC or to identify needed enhancements. These five studies were geographically diverse, conducted in Malawi; Uganda; the UK; and the USA. Two were feasibility studies, two qualitative, and one mixed methods. Study size ranged from 15 community healthcare professionals to 455 PC patients. Both African studies focused on implementation of a simple, stand-alone, EHR system designed to capture demographics and PC treatment information within low-resource settings. One feasibility study focused on whether healthcare workers could find and enter data in the system.[15] The other examined the impact of using a PC EHR in an urban and a rural setting in Uganda.[16] This study demonstrated that a simple EHR, which captured demographic information, clinical information, supply chain, and service delivery information, could significantly improve the clinical workflow and the pharmaceutical supply chain.

A qualitative study conducted among a group of English health professionals noted although they and their patients had access to a web-based pain monitoring system, the resulting data was not populating the EHR and thus, was not accessible by the interdisciplinary team.[39] Another study also noted methods to record pain data varied by profession and different groups were not only using different electronic systems, but some were still recording on paper.[38] In a feasibility study physicians found requested methods to report symptomatology such as patients being able to describe breathlessness for palliative dyspnea assessment were difficult to standardize.[14]

Communication

A study conducted in the USA described development and integration of a specialty PC module into the EHR in 2006 to capture additional demographic information, patient tracking, and patient provider communication.[4] Other enhancements focused on incorporating additional family information and communications; psycho-social assessment; and consult services referrals. The implementation was a success and the more than 20 clinical staff, ranging from physicians to nurse educators to chaplains, reported they had the needed tools and effectively and effortlessly captured an enormous amount of data.[4] Of note, many of the capabilities of the specialty module are now common features of current EHRs, but were not available 10 years ago when this project began. Another assessed the semantics used in the electronic notes recommending a PC consultation team and found if the PC team used conditional language in their recommendations in the EHR, other clinicians were much less likely to initiate PC for their patients.[42] One study, published in 2017 also in the USA, employed patient and family engagement, as well as provider feedback to identify barriers to capturing PC communication resulting in a family meeting template in the EHR.[41] The EHR then evolved so that a specialty model was no longer needed; similar information was standard. A study completed in Denmark assessed the feasibility of including caregiver support plans as part of the EHR to aid with their communication and support. Although the approach was determined to be feasible, most caregivers were too busy taking care of their

family members. Additionally, the providers felt the inclusion of caregivers raised ethical issues and were not sure that their emotional responses should be entered in the EHR.[40]

DISCUSSION

To our knowledge, this is the first published systematic review of active EHR use with PC research. Feedback from patients, caregivers, and healthcare providers highlight the need to enhance interoperability among disciplines. Although the technology is available in the EHR, the EHR is currently underutilized for PC CDS, facilitating patient-reported outcomes, and capturing ACP.

Strengths of this review included using established PRISMA guidelines, which guided a comprehensive search reviewing almost 400 articles and incorporating research from Asia, Australia, Africa, Denmark, the UK, and the USA. The broad time criteria permitted capture of the temporal increase in EHR publications over the past 5 years. The criteria of requiring publication in English limited the international scope of the review. Additionally, the terms palliative care and hospice are not used uniformly internationally with overlap depending on clinical setting and the term PC can be used in some context to refer to EOL care. For example, Stukenborg et al.[35] focused on end of life patients who needed referral to PC and Jeurkar et al.[34] used the terms palliative home patient and hospice patient within the same study. The use of ACP (or PCS) is, to date, more specific to the USA, the UK, and Australia.

The review suggests several areas in which PC clinical practice may change with further EHR workforce incorporation and a focus on a more "meaningful use" of data to improve processes and outcomes of care. As Petrova et al.[43] note in their review of electronic PC co-ordination systems in the UK, interoperability among providers and care settings is still under development and has yet to undergo rigorous research.

Future studies research should be focused on using markers in the EHR to identify specific symptoms of patient already in EOL care to improve their comfort and the quality of care.[23] Triggers will also require complementary electronic systems that facilitate direct report from patients, family, and providers who will use systems only if they feel it is improving clinical care,[2,44] especially as advanced malignancy is often not defined until discharge and frequently is not very sensitive.[45] Other suggestions included adding additional diagnosis codes to the alert system to identify specific symptoms in patients who are not yet in need of PC, but can benefit from a change in treatment course or to alleviate discomfort.[19,22]

The studies in this review demonstrated integration of patient-reported outcomes related to PC within the EHR is possible and the EHR system framework should support tracking patients, a reduction in service duplication, enhanced patient monitoring, and provide a platform for applied data analysis.[4] Incorporation of standardized patient outcomes such as PROMIS should provide uniform methodology for quantifying physical, mental, and social health across patient populations and augment comparative effectiveness analysis.[35] Integration of patient reporting has the potential to overcome common patient-provider communication barriers by collecting pre-visit patient reports electronically, delivering

results in real time at the point of care and alerting the clinician when there are severe symptoms to be addressed, potentially improving patient quality of life.[34,36]

The review indicates despite the increased focus placed on using the EHR to identify PC patients more rapidly, as well as to incorporate patient wishes and reported outcomes in the EHR, there is the need for greater inclusion. The patients studied were largely unrepresentative of general populations. For example, studies in the US were largely in academic medical systems and participants also tended to be white, have health insurance, and where reported, to be of higher education and income levels.[19,35,36] Although many of the UK studies were in large community systems, the authors also noted the lack of generalizability of studied individuals.[31] Very few studies in predominantly English-speaking countries reported having any PC materials in languages other than English.

This review identified several topics suitable for further research such as greater understanding and analysis of patient communication using the EHR. Real-time communication using the internet and computer tablets exists, but many patients do not complete the assessments, need coaching, and information is not reliably captured in the EHR.[35,36,39] More research is needed examining the associated low completion rates, feedback regarding patient-facing technology, and clinical value.

Many of the studies focused on using the EHR as either a screening approach to help healthcare providers identify patients who would benefit from PC or identify patients who had already recorded their ACPs. As Allsop et al.[32] note, electronic systems can facilitate sharing of ACP. They can be part of a system-wide commitment to patient-centered care and may be more likely to lead improvements than sole reliance on specialist PC consultations. To date, the ACP literature consists of feasibility studies or retrospective data analysis. Findings note barriers such as the cumbersome technology and the reluctance to label patients as being at EOL, are largely yet to be incorporated in process change and clinical guidance.[32]

Notably, cost was not a specific focus of most of the studies. Approaches that involve screening records or incorporating extra technology are likely to result in increased clinical administrative costs. The results of a recent quality improvement initiative conducted in a large academic, urban healthcare system concluded incorporating pay for performance incentives can be used to efficiently expand PC service to the underserved, but there were substantial administrative costs.[7] While effective PC is associated with overall healthcare savings, which may be realized in the longer term, in the short term, implementation is costly.[8,10,46]

CONCLUSION

The results of these studies presented in this system review contributed to the relevant understanding of the importance of early patient identification for PC, patient reporting, PCS, ACP, communication, and EHR enhancement for PC. The variation of methodology used in these studies resulted in one common and consistent theme, which is the EHR has yet to be optimized for its potential contributions to PC. Nevertheless, recent approaches of

CDS and PROMs demonstrated the EHR can be used to facilitate PC and to potentially result in improved PC, as well as a better quality of life for patients and their families.

Patient-reported outcomes, such as pain levels and discomfort benefit the care team, helping to change treatment course and improve patient comfort. Further studies of the role of CDS and PROMs to identify appropriate patients, establish care goals earlier in their illness as well as the potential to reduce provider discomfort when introducing the topics of PC, ACP, death, and dying are needed. Earlier and more effective PC identification can also help providers, patients, and families to discuss EOL options to match with the best type of care according to patient goals and EOL stage, improving comfort care and allowing provider to focus on offering the best intervention.

Acknowledgments

REFERENCES
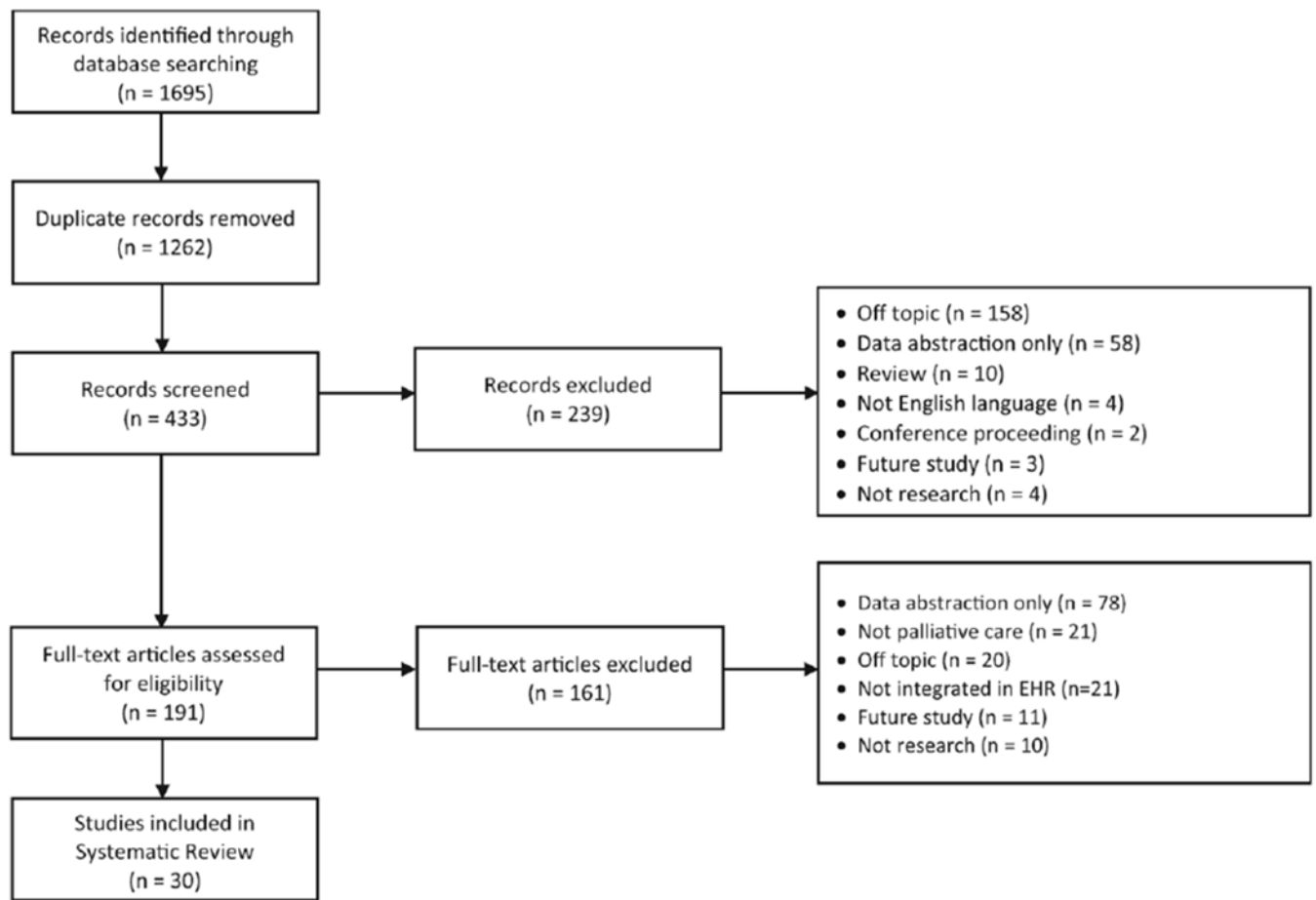
1. WHO Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/ (accessed 6 April 2017).

2. Wysham NG, Hua M, Hough CL, et al. Improving ICU-based palliative care delivery: A multicenter, multidisciplinary survey of critical care clinician attitudes and beliefs. Crit Care Med 2017;45(4):e372–e378. [PubMed: 27618270]

3. Courtright KR, Madden V, Gabler NB, et al. Rationale and design of the Randomized Evaluation of Default Access to Palliative Services (REDAPS) trial. Ann Am Thorac Soc 2016;13(9):1629–1639. [PubMed: 27348271]

4. Tsavatewa C, Musa PF, Ramsingh I. Integration of footprints information systems in palliative care: the case of Medical Center of Central Georgia. J Med Syst 2012;36(3):1511–1521. [PubMed: 21057887]

5. Martin LJ. What is palliative care. https://www.nln.nih.gov/medlineplus/ency/patientinstructions/000536.htm (accessed 21 May 2018).

6. Smith S, Brick A, O'Hara S, et al. Evidence on the cost and cost-effectiveness of palliative care: A literature review. Palliat Med 2014;28(2):130–150. [PubMed: 23838378]

7. Bernacki RE, Ko DN, Higgins P, et al. Improving access to palliative care through an innovative quality improvement initiative: an opportunity for pay-for-performance. J Palliat Med 2012;15(2):192–199. [PubMed: 22304680]

8. Aldridge MD, Hasselaar J, Garralda E, et al. Education, implementation, and policy barriers to greater integration of palliative care: A literature review. Palliat Med 2016;30(3):224–239. [PubMed: 26405109]

9. Grudzen CR, Hwang U, Cohen JA, et al. Characteristics of emergency department patients who receive a palliative care consultation. J Palliat Med 2012;15(4):396–399. [PubMed: 22468771]

10. Quest TE, Asplin BR, Cairns CB, et al. Research priorities for palliative and end-of-life care in the emergency setting. Acad Emerg Med 2011;18(6):e70–6. [PubMed: 21676052]

11. Rainone F, Blank A, Selwyn PA. The early identification of palliative care patients: preliminary processes and estimates from urban, family medicine practices. Am J Hosp Palliat Care 2007;24(2):137–140. [PubMed: 17502439]

12. Clinical Decision Support. https://www.healthit.gov/topic/safety/clinical-decision-support (accessed 22 May 2018).

13. Rhodes RL, Kazi S, Xuan L, et al. Initial development of a computer algorithm to identify patients with breast and lung cancer having poor prognosis in a safety net hospital. Am J Hosp Palliat Care 2016;33(7):678–683. [PubMed: 26140931]

14. Ahluwalia SC, Leos RL, Goebel JR, et al. Provider approaches to palliative dyspnea assessment: implications for informatics-based clinical tools. Am J Hosp Palliat Care 2013;30(3):231–238. [PubMed: 22669935]

15. Shah KG, Slough TL, Yeh PT, et al. Novel open-source electronic medical records system for palliative care in low-resource settings. BMC Palliat Care 2013;12(1):31. [PubMed: 23941694]

16. Namisango E, Ntege C, Luyirika EB, et al. Strengthening pharmaceutical systems for palliative care services in resource limited settings: piloting a mHealth application across a rural and urban setting in Uganda. BMC Palliat Care 2016;15:20. [PubMed: 26895882]

17. Moher D, Shamseer L, Clarke M, et al. Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. Syst Rev 2015;4:1. [PubMed: 25554246]

18. Neumann I, Santesso N, Akl EA, et al. A guide for health professionals to interpret and use recommendations in guidelines developed with the GRADE approach. J Clin Epidemiol 2016;72:45–55. [PubMed: 26772609]

19. Hocker JD, Khan A, Singh M, et al. Can the electronic health record identify vulnerable older adults in need of a palliative care assessment in the hospital setting? J Am Geriatr Soc 2015;63(7): 1479–1481. [PubMed: 26189857]

20. Hua MS, Li G, Blinderman CD, et al. Estimates of the need for palliative care consultation across United States intensive care units using a trigger-based model. Am J Respir Crit Care Med 2014;189(4):428–436. [PubMed: 24261961]

21. Mason B, Boyd K, Murray SA, et al. Developing a computerised search to help UK General Practices identify more patients for palliative care planning: A feasibility study. BMC Fam Pr 2015;16:99.

22. Morita T, Fujimoto K, Namba M, et al. Screening for discomfort as the fifth vital sign using an electronic medical recording system: a feasibility study. J Pain Symptom Manag 2008;35(4):430–436.

23. Yao Y, Stifter J, Ezenwa MO, et al. Infomarkers for transition to goals consistent with palliative care in dying patients. Palliat Support Care 2015;13(5):1427–1434. [PubMed: 25711431]

24. Jones BW, Bernstein C. Palliative Care Triggers in the Intensive Care Unit: A Pilot Success Story. Dimens Crit Care Nurs 2017;36(2):106–109. [PubMed: 28151788]

25. Bose-Brill S, Kobe C, Kretovics M, et al. Factors associated with age affect willingness to engage in early end-of-life communication using electronic health record-tethered patient portals. J Am Geriatr Soc 2016;64(10):e88–e90. [PubMed: 27551955]

26. Garner KK, Dubbert P, Lensing S, et al. Concordance between veterans' self-report and documentation of surrogate decision makers: Implications for quality measurement. J Pain Symptom Manag 2017;53(1):1–4.

27. Lakin JR, Isaacs E, Sullivan E, et al. Emergency physicians' experience with advance care planning documentation in the electronic medical record: Useful, needed, and elusive. J Palliat Med 2016;19(6):632–638. [PubMed: 27203483]

28. Michael N, O'Callaghan C, Baird A, et al. A mixed method feasibility study of a patient- and family-centred advance care planning intervention for cancer patients. BMC Palliat Care 2015;14:27. [PubMed: 25981642]

29. Turley M, Wang S, Meng D, et al. Impact of a care directives activity tab in the electronic health record on documentation of advance care planning. Perm J 2016;20(2):43–48. [PubMed: 27057820]

30. Dillon E, Chuang J, Gupta A, et al. Provider perspectives on advance care planning documentation in the electronic health record. Am J Hosp Palliat Care 2017;34(10)918–924. [PubMed: 28196448]

31. Ali AA, Adam R, Taylor D, et al. Use of a structured palliative care summary in patients with established cancer is associated with reduced hospital admissions by out-of-hours general practitioners in Grampian. BMJ Support Palliat Care 2013;3(4):452–455.

32. Allsop MJ, Kite S, McDermott S, et al. Electronic palliative care coordination systems: Devising and testing a methodology for evaluating documentation. Palliat Med 2017;31(5)475–482. [PubMed: 27507636]

33. Hall S, Murchie P, Campbell C, et al. Introducing an electronic Palliative Care Summary (ePCS) in Scotland: patient, carer and professional perspectives. Fam Pr 2012;29(5):576–585.

34. Jeurkar N, Farrington S, Craig TR, et al. Which hospice patients with cancer are able to die in the setting of their choice? Results of a retrospective cohort study. J Clin Oncol 2012;30(22):2783–2787. [PubMed: 22734023]

35. Stukenborg GJ, Blackhall LJ, Harrison JH, et al. Longitudinal patterns of cancer patient reported outcomes in end of life care predict survival. Support Care Cancer 2016;24(5):2217–2224. [PubMed: 26573279]

36. Wagner LI, Schink J, Bass M, et al. Bringing PROMIS to practice: brief and precise symptom screening in ambulatory cancer care. Cancer. 2015;121(6):927–934. [PubMed: 25376427]

37. Romano AM, Gade KE, Nielsen G, et al. Early palliative care reduces end-of-life Intensive Care Unit (ICU) use but not ICU Course in patients with advanced cancer. Oncologist 2017;22(3):318–323. [PubMed: 28220023]

38. Kendall M, Mason B, Momen N, et al. Proactive cancer care in primary care: a mixed-methods study. Fam Pr 2013;30(3):302–312.

39. Taylor S, Allsop MJ, Bekker HL, et al. Identifying professionals' needs in integrating electronic pain monitoring in community palliative care services: An interview study. Palliat Med 2017;31(7):661–670. [PubMed: 27836943]

40. Thomsen KT, Guldin M-B, Nielsen MK, et al. A process evaluation of systematic risk and needs assessment for caregivers in specialised palliative care. BMC Palliat Care 2017;16(1):23. [PubMed: 28390401]

41. Loeslie V, Abcejo MS, Anderson C, et al. Implementing Family Meetings Into a Respiratory Care Unit. Dimens Crit Care Nurs 2017;36(3):157–163. [PubMed: 28375991]

42. Spalding R, Kozlov E, Carpenter BD. Words Matter. Int J Aging Hum Dev 2017;85(1):123–30. [PubMed: 28466684]

43. Petrova M, Riley J, Abel J, et al. Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from. BMJ Support Palliat Care 2016 http://spcare.bmj.com/content/early/2016/09/16/bmjspcare-2015-001059.long (accessed 22 May 2018).

44. Dy SM, Roy J, Ott GE, et al. Tell Us: a Web-based tool for improving communication among patients, families, and providers in hospice and palliative care through systematic data specification, collection, and use. J Pain Symptom Manag 2011;42(4):526–534.

45. Hua M, Li G, Clancy C, et al. Validation of the V66.7 code for palliative care consultation in a Single Academic Medical Center. J Palliat Med 2017;20(4):372–377. doi:10.1089/jpm.2016.0363. [PubMed: 27925839]

46. Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med 2008;168(16):1783–1790. [PubMed: 18779466]

Figure 1.
Search Results

Table 1.

Search Terms

Terms
Palliative and ehealth
Palliative and EHR
Palliative and EMR
Palliative and electronic decision support
Palliative and electronic health record
Palliative and electronic medical record
Palliative care and ehealth
Palliative care and EHR
Palliative care and EMR
Palliative care electronic decision support
Palliative care electronic health record
Palliative care and electronic medical record
Palliative medicine and ehealth
Palliative medicine and EHR
Palliative medicine and EMR
Palliative medicine and electronic decision support
Palliative medicine and electronic health record
Palliative medicine and electronic medical record

EHR:electronic health record; EMR: electronic medical record.

Table 2.

Summary of study design and key findings of publications on PC and EHRs

References, Region	Study design, population, and sample size	Decision element EHR decision element	Results
Alert			
Hocker, et al.,[19] USA	Feasibility study in of 92 adults >65 admitted to medical-surgical units in mid-western healthcare system.	Alert: real-time CDS to identify individuals who might benefit from PC.	Individuals identified through alert were more likely to have social services assessment. Those not identified had higher 6-mo mortality rate.
Hua, et al.,[21] USA	Retrospective cohort study of ICU patients using Project IMPACT data set.	Alert: multiple potential triggers tested among ICU patients to identify patients appropriate for PC consultation.	Five triggers captured 85% of appropriate patients: ICU admission after hospital stay 10 d; multisystem organ failure 3 systems; Stage IV malignance; status post-cardiac arrest; intracerebral hemorrhage requiring mechanical ventilation.
Mason, et al.,[21] UK	Feasibility study of ~83,000 records reviewed from 12 primary care practices in UK	Alert: CDS to alert GP to screen for deteriorating health among patients with any advanced condition for PC and assessing how primary care clinicians use results to improve patient care	Identified patients appropriate for but not already on PC registry. Most common action taken by GP was to start an electronic anticipatory care plan.
Morita, et al.,[22] Schizuoka, Japan	Feasibility study of 629 male and female oncology patients screened for discomfort in a Japanese 700 bed cancer hospital	Alert: CDS automatically screened pain scores; produce trigger for PC team	Identified undertreated symptoms. Feasible to identify patients with considerable physical discomfort using EHR; no patient burden; minimal nursing burden. Facilitated earlier PC referral.
Rhodes, et al.,[13] USA	Retrospective cohort study of 369 breast and lung cancer patients in a large urban safety net hospital in USA.; 63% non-hispanic/black	Alert: created electronic algorithm to identify advanced cancer patients who could from PC	First generations sensitivity was 21% and specificity 96%. Other advanced illness markers will be added to improve the next versions of the algorithm.
Wysham, et al.[2] USA	Mixed Methods study; 303 nurses, intensivists, and advanced practice providers from medical and surgical ICUs at three large academic hospitals.	Alert: written survey evaluating clinician attitude and beliefs regarding PC consultation integration in ICU as well as evaluation of current PC trigger and alert methodology.	Most respondents view integration of PC in ICU favorably. Although current triggers for PC consultation were easily extracted from EHR and other triggers preferred, preferred triggers more difficult to obtain.
Yao, et al.,[23] USA	Retrospective secondary analysis of 901 deceased patients, from four mid-west hospital EHR data warehouse.	Alert: evaluation of 11 diagnoses that when added to nursing patient care plans are marks of patient transition to PC.	EHR contains markers that may be used for timely referral to PC and related focus on improved focus on comfort. Many patients who could benefit did not receive PC.
Jones, and Bernstein,[24] USA	Pilot Study; testing effectiveness of four triggers to identify ICU patients in a multisite hospital system for PC referral.	Alert: implement four palliative triggers in the ICU system in order to monitor the effect on referrals to the PC program.	There were 11 consultation orders in the first month, compared to 27 total referrals the previous year. Among surveyed providers, 90.63% of the responders agreed that PC has provided great benefit to patients and their families.
ACP			
Bose-Bill, et al.,[25] USA	Prospective, convenience sampling survey of 72 participants (age >= 50) at a mid-west primary care clinic	ACP: examine factors associated with individual willingness to communicate with primary care provider and to use patient portal to facilitate ACP completion.	Participants younger than 70 more likely to find electronic ACP useful compared to those 79 and older.
Garner, et al.,[26] USA	Retrospective secondary data analysis; 505 patients from a VA hospital in Arkansas	ACP: measure veteran completion of advanced directive documentation in EHR.	Majority of veterans (73%) said they had talked to someone about making decisions for them and 61% said they had named someone to make decisions, however, 67% did not have an advanced directive in the EHR.

References, Region	Study design, population, and sample size	Decision element EHR decision element	Results
Lakin, et al.,[27] USA	Cross-sectional survey of 86 ED attending physicians and residents in large academic hospital.	ACP: measure ED physician confidence in finding and using ACP documentation in the EHR	Majority of respondents agreed ACP documentation and EHR systems important but lack confidence to find ACPs. Legal forms more useful than documentation about ACP discussion. Suggested ACP information needed to be in one consolidated place in EHR.
Michael, et al.,[28] Australia	Prospective, longitudinal, mixed methods with convenience sampling; 30 patients and 26 caregivers in large specialist oncology facility in Australia.	ACP: evaluation of scripted approaches with patients and caregivers to discuss and to complete an ACP within the EHR.	Very low participation. ACP complicated, emotional process. Flexibility and individual approaches needed.
Turley, et al.,[29] USA	Retrospective Cohort study; 113,309 patients >=65 at US managed care health system.	ACP: Describe ACP documentation rates before and after implementation of single-location tab in EHR for Care Directives	Analysis predominantly but not exclusively PC patients. Documentation rates for ACP were 3.5 to 9.6 higher, depending on patient encounter type, after introduction of designated tab. Suggests standard location in EHR improves documentation.
Dillon, et al.,[30] USA	Mixed methods with structured interviews with 13 primary care and specialty providers, and summary statistical analysis of 358 primary care and 79 specialists EHR data	ACP: structured interviews conducted with high and low ACP providers to identify barriers. ACP rates calculated for all providers in primary care and various specialists.	PCPs document ACP more than specialists. PCPs believe ACP documentation is beneficial and accessible, while specialists believe that creates more confusion and frustration due to the lack of interoperability. between the hospital and the outpatient EHR systems.
Ali, et al.,[31] UK	Retrospective cohort study; database of 401 patients with established cancer.	ACP: determine if PC summary in EHR, introduced in UK in 2009, would facilitate community patient care and influence emergency admission to hospital during out of hours	Absence of an ACP significantly increased likelihood of hospital admission.
Allsop, et al.,[32] UK	Project review and objective evaluation to detect problems and inform IT redesign using; retrospective analysis of 1229 deaths recorded in electronic PC co-ordination system.	ACP: evaluated proportion of deceased patients who had end of life care preferences in their EHR.	Approximately 25% of those with cancer, circulatory, and respiratory disease had documentation in place. Most documentation completed 8 d before death.
Hall, et al.,[33] UK	Qualitative interviews using purposive sample of 22 health professionals.	ACP: identify facilitators and barriers to use of ACP	General satisfaction with ePCS among all. Greatest concerns were related to implementation issues including learning new processes. Most practice were only completing summaries for their cancer patients rather than all patients with PC needs.
PRO			
Jeurkar, et al.,[34] USA	Retrospective secondary data analysis; 7391 oncology patients (89% white) from three hospice programs	PRO: extraction of patient question regarding end of life preferences embedded in EHR admission form	Examined patient characteristics, including PC score, with place of death. Documentation of desire to die at home associated with home death.
Stukenborg, et al.,[35] USA	Mixed methods evaluation patient trajectory and patient-reported outcomes; 472 patients (82% White) in PC program at academic healthy system cancer center	PRO: collection of PROMs using software integrated within patient's EHR and accessed online using a computer tablet.	PROMs such as depression, fatigue, pain, and physical function were used to estimate patients' deteriorating health status toward end of life.
Wagner, et al.,[36] USA	Feasibility study; 1493 women (78% white) in outpatient oncology academic clinic	PRO: women receiving gynecologic oncology outpatient care completed PROMIS computer adaptive test through a patient portal; interdisciplinary	Demonstrated ability to integrate administration and scoring of ePRO within EHR. Approximately 80% participated initially but fewer than third completed entire assessment. Impaired

References, Region	Study design, population, and sample size	Decision element EHR decision element	Results
		palliative response based on reported symptoms	physical functioning most common response trigger
Romano, et al.,[37] USA	Retrospective cohort study of 275 patients with advanced cancer enrolled in an early PC program, and 195 patients with advanced cancer receiving standard care in an academic hospital.	PRO: patients completed a PRO assessment that included health domains measured by the NIH PROMIS instrument and symptom-specific assessment.	Control group patients had higher adjustment odds of ICU admission during the last 6 months, higher odds of death in the hospital or in the ICU, and they were significantly less likely to be enrolled in hospice.
Enhanced EHR			
Namisango, et al.,[37] Uganda	Feasibility study; 455 patients at an urban hospice and rural district hospital in Uganda	Enhanced EHR: EHR created for PC services including demographic information; clinical information; supply chain and service delivery information. Used internet connected tablets with portable power packs	Captured pain scale, medications, and used of laxatives. Improved patient record management and supply planning. Provided better control of opioids.
Shah, et al.,[15] Malawi	Feasibility Study; evaluation usability of EHR designed for PC providers in low resources setting. Healthcare professionals at a private hospital and largest government run central hospital participated.	Enhanced EHR: open sourced and PC specific EHR	With minimal training hospital staff able to organize administrative data; create a patient registry; maintain and generate reports of comprehensive PC unit reports.
Kendall, et al.,[38] UK	Mixed-methods action research; 107 patient records, 16 patients and caretakers interviewed; 29 health professionals interviewed	Enhanced EHR: an electronic ongoing review template developed by patients and professional and implemented	Template was helpful in structuring consultations and covering psychosocial areas but not well integrated within electronic medical record; template often completed after patient visit rather than concurrently.
Ahluwalia, et al.,[14] USA	Qualitative Interview; 13 PC providers at VA	Enhanced EHR: qualitatively evaluate end-user practices and preferences for EHR based dyspnea assessment tool	Need integration of patient self-report of breathlessness with a clinical observation of dyspnea; difficult to capture individual clinical experiences in a standardized application. Clinician variability in preference for and use of existing severity scales for dyspnea.
Taylor, S.	Purposive sampling of 15 health professionals using qualitative semi-structured interviews	Enhanced EHR: PC pain monitoring application.	Electronic, web-based system, for pain monitoring does not integrate into the existing EHR system. Also issues with varied methods of recording patient data across disciplines and different systems that do not speak to each other.
Communication			
Tsavatewa et al.[4] USA	Feasibility study; 20 clinicians and administrators in an academic medical center	Communication: PC service records integrated into hospital's existing EHR providing virtual environment with real-time updates by computer, tablet, and telephone.	Patient-centric data available and guided clinical decisions. Additional technology permitted standardization of information collection; improved access to the information; enhanced monitoring of patient status
Thomsen et al.,[40] Denmark	Feasibility study; 16 family palliative caregivers in Danish PC home care program.	Communication: expand EHR to allow for bereavement support for caregivers including needs assessment, support plan, support, and documentation.	Evaluation difficult as caregivers busy with PC patient. Inclusion into HER controversial among clinicians. Ethical concerns about emotional content.
Loeslie et al.,[41] USA	Feasibility study: patients, families, and staff on respiratory care unit, use standardized electronic template to facilitate family meetings/conferences.	Communication: electronic template was created for documentation of family meetings in the EHR.	Multiple communication barriers were identified including time and coordination, language barriers, caregiver/family comfort. After implementation, the frequency of family meetings occurrence rose from 31% to 88%. Patient/family satisfaction

References, Region	Study design, population, and sample size	Decision element EHR decision element	Results
			improved, as well as efficacy communicating with their medical team. Clinicians were also positive.
Spalding et al.,[42] USA	Retrospective secondary data analysis; 198 individual EHRs reviewed for PC recommendations in a VA	Communication: semantics of PC recommendations evaluated to determine the proportion of PC recommendations implemented by other providers.	Conditional recommendations less likely to be implemented. How PC The style used to chart PC recommendations in the EHR affects patient treatment.

EHR, electronic health record; ACP: advanced care planning; EMR: electronic medical record; IT: information technology; PC: palliative care; ePCS: electronic palliative care summary; ePRO: electronic patient-reported outcomes; PRO: patient reported outcome; PROM: patient reported outcome measure; QI: Quality Initiative; VA, Veterans' Affairs; GP: general practitioner; CDS: clinical decision support; ICU: intensive care unit; ED: emergency department.