Improving End-of-Life Care in the Primary Care Setting: Implementation of the Serious Illness Care Program

Rey Jericoh Manalese

Arizona State University

Abstract

Early and effective end-of-life care are associated with increased quality of life for those patients who may be nearing the end-of-life (EOL). However, evidence suggests that most non-palliative healthcare providers lack the skills and confidence to initiate EOL conversations. Consequently, about 70% of Americans would prefer to die at home with their families, yet only 25% die according to their wishes (State of California Department of Justice, n.d). In alignment with the Peaceful End of Life Theory, the purpose of this evidence-based project is to increase primary healthcare providers' level of skills and confidence in end-of-life discussions. This project utilized a pre and post study design. A total of 11 participants were recruited using convenience sampling from three primary care clinics in Phoenix, Arizona. Due to the small sample size and assumption of a non-normal distribution of the data, Wilcoxon Signed Ranks test and Pearson correlation coefficient were used for statistical analysis. There were clinical and statistical significant improvements in the EOL knowledge of the participants after the implementation of the two-and-a-half-hour Serious Illness Care Program ($Z = -2.950$, $p = .003$) with a large effect size ($r = -0.62$). The project evaluation also demonstrated that most participants deemed that the intervention was effective. A brief and systematic education session, such as the SICP can be utilized to improve non-palliative healthcare providers' skills in having more and effective end-of-life conversations.

Keyword: End-of-life care, advance care planning, palliative care, primary care providers, healthcare providers

Improving End-of-Life Care in the Primary Care Setting

End-of-life (EOL) care is essential to meet patients' preference in care as they approach the final days of their lives. For non-palliative healthcare personnel, primary care providers, including Registered Nurses (RN), Social Workers (SW), Nurse Practitioners (NP), Physician Assistants (PA) and Physicians are in the forefront to initiate EOL conversations due to the trusted and lasting relationships that they have with their patients. However, despite this integral position of the primary care clinicians to discuss EOL care with their patients, many fail to do so. According to Periyakoil, Neri, and Kraemer (2015), the population of older adults will be about 71 million by the year of 2030 and approximately 80% of this population will suffer from chronic illnesses before dying. With the growing number of the population who may need palliative care, there has been an increased effort to improve the knowledge and skills of non-palliative healthcare providers in EOL and palliative care.

Problem Statement

The impact of one's death can affect multiple people including the patient's family and friends. Evidence suggests that with proper EOL care planning, such as discussion of wishes, beliefs, and goals, patients are more likely to have a better quality of life, receive the care that they want, and have a more peaceful death (Nyatanga. 2014; Lakin et al., 2016). However, in today's modern healthcare industry, EOL care has been given little attention, and the likelihood of dying in the hospitals rather than according to the patient's preferences continue to rise (Giovanni, 2012). In the United States, Medicare beneficiaries in some western and northwestern states had about 20% chance of dying in the hospital, while southern and eastern states were estimated to be more than 50% (Giovanni, 2012). The National Institutes of Health (2010) reported that more than 20% of all United States deaths occur in or shortly after an ICU stay, which also leads to family members experiencing stress, fear, depression, and anxiety.

The types of care patients receive toward the end of life in inpatient-based hospitals are also causing a burden to the healthcare economy. Patients who did not have EOL care discussions with their healthcare providers are more likely to utilize intensive care units and emergency room visits compared to patients who had early EOL planning (Kim & Tarn, 2016). The Medicare Payment Advisory Commission (MedPAC) reported that about a quarter of the Medicare budget is spent on members who are in the last year of their life, and 40% of that is in the last 30 days of their lives (Giovanni, 2012). Healthcare costs toward the end of life and lack of proper EOL planning could increase as the number of older Americans is predicted to reach 72.2 million by 2050 (Giovanni, 2012). In the state of Arizona alone, the entire population is expected to grow from almost 6.5 million in 2010 to 11.5 million in 2050. The number of Arizonans aged 65 and above is expected to increase 174% from nearly 900 thousand in 2010 to 2.5 million in 2050 (Arizona Department of Health Services, n.d.).

The Centers for Disease Control and Prevention (2014) reported that only about one-third of adults have an advance directive that expresses their wishes for EOL care. In addition, most primary care providers receive inadequate or no training in communicating goals of care for patients who may be nearing the end of life or are seriously ill (Lakin et al., 2016). The Agency for Healthcare Research and Quality reported that only 12% of patients with advance directives had received input from their physicians in its development (As cited in Kirk, 2010).

In 1997, the Institute of Medicine (IOM) published a report, which discussed the problems and concerns of the community in caring for people who are nearing end of life. In the report, the IOM recognized the vast need to improve the quality of EOL communications with both the patients and their families. The IOM mentioned that the education of many healthcare providers does not equip clinicians with enough knowledge and skills in palliative or EOL care to effectively care for patients who may benefit with EOL discussions.

Furthermore, the pragmatic practice in EOL care is also globally recognized. The World Health Organization (2017) estimated that there are 40 million people in need of palliative care and only about 14% received some type of palliative care services. In Europe, a qualitative focus study conducted by Selman et al., (2017), which included 28 healthcare providers, exposed the gap in the end-of-life care knowledge of general practitioners. According to the study, most general practitioners perceive end-of-life care to be both clinically and emotionally challenging.

In the present time, little has been done, as many non-palliative healthcare providers are still unsure of when and how to discuss EOL care. In recent polls generated by the California Health Care Foundation (CHCF) (2016), which includes 762 primary care and various specialist physicians, 46% reported that they had experienced significant barriers to having EOL discussions. The national government of the United States also acknowledged the poor quality of EOL care in the country and started to view it as a public health problem. As a response, Center for Medicare and Medicaid Services (CMS) made it possible for clinicians to receive reimbursement when providing advance care planning or EOL discussions with the patient (California Health Care Foundation, 2016). Despite the addition of the reimbursement for advance care planning, only 14% have billed Medicare for advance care planning conversation since its inclusion on January 1, 2016 (California Health Care Foundation, 2016). With the mounting evidence regarding the gap in knowledge of the primary care providers in EOL communication, there is a need to improve the knowledge, skills, and comfort with EOL discussions among primary healthcare providers (Reed et al., 2017; Lakin et al., 2016; Selman et al., 2017).

Purpose and Rationale

In 1995, a landmark study of end-of-life care was conducted to measure the quality of life of patients nearing the end of life after the implementation of an improved EOL care. In phase one of the study, the analysis of the multisite delivery of EOL care revealed a significant gap in communication and frequency of life-supporting treatment (Connors et al., 1995). Therefore, it is historically known that poor discussions about EOL care resulted in unwanted treatments and poor quality of life. Thus, the purpose of this project is to discuss the significance of the problem including the external and internal evidence regarding EOL care and implement an evidence-based intervention that could improve EOL communications.

Background and Significance

Primary Care Providers

The need for all healthcare providers to deliver EOL or palliative care has come into a view as patients' needs are outweighing the number of palliative providers. The primary care providers have important role in delivering EOL care (Kim & Tarn, 2016). In addition, primary care providers are in the perfect position to initiate EOL discussions as they have long-standing relationships with their patients and may know more about the wishes and desire of their patients (Kim & Tarn, 2016). However, the frequency of EOL conversations is lacking according to the literature. Kale, Ornstein, Smith, and Kelley (2016) suggested in their retrospective study (N= 1993) that a vast majority of older adults enrolled in Medicare had not discussed their preferences regarding EOL. Forty percent of this nationally representative sample of Medicare members reported that they have not discussed any EOL planning.

Little is known about the engagement of the public in EOL discussions. However, increasing frequency and discussions of EOL plans and wishes have been associated with care that is consistent with patients' values and beliefs. Kim and Tarn (2016) conducted a systematic review which concluded that when primary care providers are involved in EOL care, there is a decrease incidence of deaths in the hospital, more deaths at home or hospice care, better death preparation, and better symptom control before dying. In another systematic review, Green, Knight, Gott, Barclay, and White (2018) reported that patients who are treated by specialists are being reassured and reverted back to their general practitioners for palliative and EOL care. Many patients view general practitioners or primary care providers to be well-placed to provide palliative care; therefore, it is critical that primary care providers have the knowledge and confidence to engage in EOL discussions.

End of Life Knowledge

One widely known theme in the literature is the gap in the knowledge and skills of non-palliative healthcare providers in the specific approach to EOL discussions. Nedjat-Haiem and colleagues (2017) reported that both medical and non-medical providers, such as nurses, social workers, chaplain, and physicians are unclear about their role and failed to clearly describe their responsibility in providing EOL care. Moreover, the model of education of most healthcare providers do not sufficiently emphasize EOL care. As a result, non-palliative clinicians feel unprepared to discuss EOL care with their patients (Selman et al., 2017; Gillan, Van Der Riet, Jeong, 2014). In the systemic review conducted by Gillan, Van Der Riet, and Jeong (2014), the finding suggests that most undergraduate nursing education are not adequately preparing students to provide EOL care. Nursing students who are involved in the study reported that they feel unprepared to engage in communication regarding EOL discussions. The current nursing education is lacking content and depth in how to care for patients who are nearing the end of life (Gillan, Van Der Riet, & Jeong, 2014). Selman et al. (2017) also demonstrated the lack of confidence and comfort of general practitioners in their qualitative focus group study. Majority of the participants in the study discern the educational needs in EOL care. Also, Dunlay et al. (2015), conducted a multisite clinician survey study which involved physicians, nurse practitioners, and physician assistants who work with patients with heart failure suggested that there are variabilities on how providers approach EOL discussion. It was found that cardiologists and heart failure specialists are less likely to engage in EOL conversation as they felt that this is the responsibility of the primary care providers. In fact, Kim and Tarn (2016) demonstrated in their study that involvement of primary care providers in EOL care resulted in decrease in hospital visits, decrease in healthcare costs, and improvement in communication.

Barriers

According to the literature, different barriers exist in having effective EOL discussions between primary care clinicians and patients. In fact, a mixed-method study of multi-specialty doctors caring for seriously ill patients discussed the different barriers in initiating EOL conversations (Periyakoil, Neri, & Kraemer, 2015). The study demonstrated the six primary barriers and ranked them in order; (1) language and medical interpretation issues, (2) patient or family religious and spiritual beliefs about dying, (3) providers' ignorance of patient's cultural beliefs, values, and practice, (4) cultural differences, (5) patients' limited health literacy, (6) and patients' mistrust of doctors and the healthcare system. Moreover, 1032 doctors or 99.9% of the participants acknowledged some type of barriers in conducting EOL conversations. Pippa (2017) noted that other well-documented reasons for the lack of palliative care discussions are fear of upsetting the patients, seeing referral as an admission of failure, and not understanding the benefits of palliative or EOL care.

Education

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) study, which is the landmark study for the EOL care research, randomized seriously ill patients that were hospitalized to an intervention arm that facilitated increased patient-clinician communication (Fakhri, 2016). The study found no significant effect after implementing the intervention. The study set the foundation for various initiatives to improve communications between patients and healthcare providers.

Nevis (2014) analyzed the effectiveness of various educational interventions for healthcare providers in improving EOL care. Although the study concluded that there was no significant improvement in the quality of life of the patients, it showed improve symptom control for patients and quality of life for informal caregivers. The study suggests that there is a need to develop a more effective and structured communication approach to EOL care. Moreover, Lakin et al. (2017) implemented the Serious Illness Care Program (SICP) aimed to improve access to high-quality communication for patients with serious illnesses. The focus of the SICP is to promote conversations that emphasize what is important for the patients. The clinics and clinicians selected for the intervention arm of the study reported that the training is highly effective and engaged in a higher number of EOL care discussions (72.7%) compared to the comparison clinic (39.6%). The types of participants in both the intervention and comparison groups were physicians, nurse coordinators, and social workers. The finding from the study suggests that a brief and structured educational program can increase the frequency of discussion and quality of EOL care in the primary care clinics.

Furthermore, the lack of knowledge and confidence of nurses in EOL care led to a descriptive cross-sectional study, which aimed to analyze the pre and post assessment knowledge in palliative care of senior nursing students (Glover et al., 2017). In the study, a two-day course derived from the End-of-Life Nursing Education Consortium (ELNEC) program was utilized to improve the knowledge of nursing students. Although most of the students deemed the program long, the post response from the students indicated improved knowledge about EOL care and communication skills with the dying patients. The study suggested that educating nurses about EOL care can positively impact their knowledge and approach to palliative care.

Internal Evidence

In Arizona, Governor Ducey signed the Advance Directive Bill to form a process that allows healthcare providers to have access to the state's Advance Directive Registry on or before December 31, 2018 (Arizona Hospital and Healthcare Association, 2017). The goal was to optimize communication, decrease unnecessary and unwanted interventions, and respect the wishes of patients towards the EOL. The Arizona Hospital and Healthcare Association (AzHHA) is one of the supporters of this policy, and the organization was awarded one million dollars of grant money from the Lura Lovell foundation to improve EOL care in Arizona. The increasing efforts in Arizona to promote advance care planning and effective EOL care suggests that there may be a need to improve the education of non-palliative clinicians to assist in better EOL communication. In addition, EOL care discussions in various primary care clinics in Arizona still has low occurrences. This preliminary inquiry about the background and significance of EOL care has led to the clinically relevant PICO question, "Among primary care providers, how does implementation of Serious Illness Care Program compare to no intervention influences primary care providers' skills in discussing EOL care?"

Search Process

A comprehensive search of the literature was conducted to understand and appraise different studies related to EOL care in the primary care setting, barriers in EOL discussions, and effectiveness of an educational intervention in improving EOL care. The databases included in the search were PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and Academic Search Premier. Various studies and systematic reviews were determined by utilizing different combinations of keywords and Medical Subject Headings (MeSH) terms. The keywords and phrases included in the comprehensive search were the following: “end-of-life care,” “palliative care,” “advance care planning,” “terminal care,” “healthcare provider,” “primary care,” “nurse,” “social worker,” “barriers,” “knowledge,” “education,” “training,” “serious illness communication,” “communication,” and “frequency.” The initial search of the keywords “end-of-life care,” “advance care planning,” “palliative care,” or “terminal care.” The initial search yielded 82,507 results in PubMed (Appendix A), 1,940 in CINAHL (Appendix B), and 1,093 in Academic Search Premier (Appendix C). By setting limits to publication date ranging from 2012 to 2018, applying MeSH terms, Boolean/phrase, such as “primary care,” “healthcare providers,” “training,” “knowledge,” or “barriers,” the overall search yielded 188 studies from PubMed, 132 studies from CINAHL, and 201 studies from Academic Search Premier.

The inclusion criteria consisted of studies in English text, addressed EOL care or discussions, focused on adult patients who were nearing EOL, and focused on various healthcare providers. The exclusion criteria included studies involving pediatric population and studies that were not written in English language.

Critical Appraisal and Synthesis

The search yielded 20 articles and each article was rated according to the strength of evidence and overall quality of the study using the Rapid Critical Appraisal (RCA) checklist. After reviewing each study, ten articles were included in this review. Three qualitative studies, two mixed-method study, one retrospective study, one prospective study, and three randomized controlled trial (RCT) studies were used in this review (Appendix F). Although the RCT studies utilized measuring tools that are well known in the field of research, none of the studies listed information about the specificities and sensitivities of the measuring instruments. Also, one RCT study that tested the effectiveness of SICP lack the detailed information about the methodology, as only preliminary information was given. The three qualitative studies and two mixed-method studies explored the role and insights of various non-palliative healthcare providers in EOL care. The retrospective cohort study demonstrated the effectiveness of a brief educational intervention in improving EOL care communication. In addition to the RCT, the prospective implementation trial that used SICP as the intervention added quantifiable data regarding the effectiveness of a brief education intervention in improving quality of EOL conversations. Also, the three RCT and one mixed-method study provided more quantifiable information about the effectiveness of various EOL education interventions for healthcare providers. The Cronbach's alpha was exclusively searched to measure the internal consistency of the various tools used in the RCT studies. Most Cronbach's alpha from RCT studies produced acceptable results as shown in the Appendix F of this paper.

The reliability and validity for RCTs were assumed based on statistically significant results and Cronbach's alpha score of the studies. Although not all of the desired outcome measurement was achieved, most of the measurement tools used in the studies produced statistically significant results that pertains to their own respective interventions. Lakin et al. (2017) used Rao-Scott chi-square test and t-tests for various descriptive and outcome variables, which also yielded statistically significant results. In addition, a large clinical significance was seen across all the studies and most produced statistically significant results (Appendix F). The three qualitative studies provided an appropriate choice for methodology including sampling, data analysis, and validity of the results (Appendix F). There was minimal bias across all the studies.

There was a moderate degree of homogeneity identified across all the studies in regard to the demographics, interventions, and variances. The majority of the participants were registered nurses, physicians, and nurse practitioners. Most healthcare provider participants were between the age of 40 and 70. All patients involved in the studies had chronic illnesses and may benefit from EOL conversations. All education interventions produced clinically significant outcomes in the knowledge and frequency of EOL communications among non-palliative healthcare providers. Also, there was a mild degree of heterogeneity in regard to the focus of outcomes studied. The three RCT studies measured the effect of EOL discussions in regard to the quality of life of patients and their families, while other studies were focused on the effect of the intervention to the healthcare providers.

Conclusion

Overall, the most common theme from the literature was the inadequate knowledge of many healthcare providers in EOL discussions and infrequency of EOL communications in the primary healthcare setting. A brief, structured, and interactive educational tool may provide healthcare providers with skills that can improve their confidence in initiating EOL care discussions. The Serious Illness Care Program (SICP) is a brief educational intervention that can improve knowledge of healthcare providers and occurrences of EOL communication (Appendix F). Lakin and colleague’s (2017) prospective study demonstrated that SICP, a two-and-a-half-hour educational program that involves role playing, was statistically effective in increasing frequency and access to high quality EOL discussions. Paladino and colleagues (2016) further demonstrated with their cluster-randomized controlled trial that SICP may be a scalable intervention to promote early, better, and more EOL conversations. Overall, this literature review suggests that SICP is a brief and cost-effective intervention that may improve EOL care in the community, especially in the primary care, thus increasing patients' quality of life and promoting more peaceful EOL experience.

Theoretical Framework

The theoretical framework utilized for this study was the middle-range theory called the Peaceful End-of-Life (PEOL) (Ruland & Moore, 1998). PEOL theory focuses on contributing a peaceful and meaningful life towards the EOL for patients and their families have (Ruland & Moore, 1998). Ruland and Moore (1998) suggested that caring for terminally ill patients is complex, and it requires knowledge not only of controlling symptoms and managing pain, but compassion and awareness to the patients' beliefs and wishes. There are five main concepts proposed in the Peaceful End-of-Life theory: not being in pain, experience comfort, experience dignity and respect, being at peace, and closeness to significant others (Appendix D). These concepts suggest that the goal of end-of-life care should not be about aggressive treatments or optimizing treatment plans for curative purposes, but rather should focus on providing comfort for the patient while honoring his or her values. The central goal of this theory is to adjust treatment based on comfort measures, enhanced quality of life, and ultimately promote a peaceful death (Ruland & Moore, 1998). Ruland and Moore (1998) also suggested that nurses have the responsibility to facilitate the participation of the patient's families to promote family closeness and emotional support, which leads to experience of being at peace.

The five concepts of the Peaceful End-of-Life theory can guide nurses in selecting interventions that will lessen the suffering and help the patients to have a meaningful end-of-life experience (Appendix D). The PEOL theoretical framework may remind healthcare providers that the focus of treatment should always be based on the patient's goals and wishes thus, making EOL experience more peaceful for the patients and their families.

Innovation Model

The Rosswurm and Larrabee's Model for Evidence Based Practice Change was adopted to guide this project. The Rosswurm and Larrabee's model comprises of six stages: assess need for change, link problem with interventions and outcomes, synthesize best evidence, design a change in practice, implement and evaluate the practice change, and integrate and maintain the practice change (Appendix E). The first stage is to assess the need for change in practice, which involves identification of internal and external data to substantiate the need for practice change. An exhaustive search and interview of stakeholders led to the comparison of internal and external data of current EOL practice which also resulted to the identification of the problem. Second, linking the problem with the best intervention based on evidence is critical for this model. In this project, inclusion and exclusion criteria was set to achieve the best possible evidence in the development of the PICOT and project intervention. Third, synthesizing the best evidence by critically analyzing various studies with the use of rapid critical appraisal tool to refine selected interventions and studies was used in this project. Critically appraising different studies was performed to determine whether the strength of intervention or study supports a change in practice. Fourth, it is critical to define the practice change by designing the implementation plan and evaluation strategies. The synthesis of evidence revealed that the use of various educational interventions to increase confidence and knowledge of healthcare providers in EOL care discussions was statistically effective. The fifth step is implementing the chosen intervention with the use of evidence-based implementation of the project, evaluating the outcome, and developing conclusions and recommendations for future practice. The recommended practice change for this project is to implement a brief education training for healthcare providers that may improve the quality and frequency of EOL discussions in the primary care setting. The final step is integrating and maintaining practice change. The adoption of the Rosswurm and Larrabee's model provided this project with a systematic step-by-step approach for developing and implementing an evidence-based practice change (Appendix E).

Brief Plan for Applying Evidence to Practice

Primary care providers play a vital role in implementing EOL care planning. Early and effective EOL discussions have been associated with decrease fear in dying and promote a peaceful death for patients who may be nearing the EOL. However, the literature suggests that many primary care providers are confused about their roles and do not have the knowledge to initiate EOL conversations. The stakeholders affected by this problem are nurses, nurse practitioners, physician assistants, physicians, social workers, patients, and families. The potential data to be collected for this project is the pre and post information regarding the healthcare providers' knowledge or skills about EOL care communication. Moreover, a survey was given to the participants to evaluate the effectiveness of the course content and components of the training. The intervention selected for this project was the Serious Illness Care program (SICP), which is a two-and-a-half-hour educational program that may equip providers with skills and system-level support needed to carry on a comprehensive goal of care conversations. This evidence-based project was conducted in collaboration with the AzHHA. AzHHA provided all coaching resources and trainings necessary to properly conduct the two-and-a-half-hour workshop to non-palliative healthcare providers. This project was inspired by the AzHHA and their goal to improve end of life care for Arizonans. Change in the skills and knowledge of primary healthcare providers in EOL care were measured using a self-report questionnaire and recorded for comparison to the baseline score. All participants were also given a satisfaction survey to assess the effectiveness of the SICP.

Methods

Design

The study design for this project was a pre and post-test design, which was based on the innovation model of the Rosswurm and Larrabee's Model for Evidence Based Practice Change. The theoretical framework used for this project is the Peaceful End-of-Life theory by Ruland and Moore.

Ethics

The project design was submitted and approved by the Arizona State University Institutional Review Board (IRB) committee. In keeping with the university IRB requirements, all personnel who had access to the data have been formally trained in the protection of human subjects before working with the participants or having access to the data. The risks associated with breaches of confidentiality or anonymity were minimized by using anonymous pretest and posttest survey data which was saved and managed in a secure computer accessible only by the author. Although the proposed project had minimal potential for adverse events, the author monitored participants by carefully listening and observing the communication between the author and participants.

Sample and Sampling

A sample of 11 participants were recruited from three different primary care clinics in Phoenix, Arizona. Convenience sampling was utilized for this project. The inclusion criteria were adults aged 18 and above who (1) identify themselves as primary care providers, such as registered nurses, nurse practitioners, physician assistants, physicians, licensed social workers (2) are able to read, write and understand English; (3) agree to provide consent. Participants who did not meet all criteria or declined participation were excluded.

Procedure

Participants were identified in collaboration with primary care providers and mentors from Arizona Hospital and Healthcare Association. The author visited three primary care clinics and handed recruitment flyers to the clinic managers and clinicians. Clinicians who were interested to participate contacted the author via the information provided on the flyer. The author also contacted potential participants identified and referred by other primary care providers. For the initial meeting with participants, the author explained the purpose of the project, procedure, and potential risks and benefits of participating in the project. Primary care providers who gave consent and participated were enrolled.

Eligible participants who gave consent were invited to attend in a two-and-a-half-hour SICP educational presentation held in locations that were appropriate for implementation of the project. Project implementation sites included conference room at the Arizona Hospital and Healthcare Association office, public libraries, and coffee shops. In the beginning of the presentation, a demographic questionnaire and pretest survey or baseline assessment of each provider’s current knowledge and confidence in EOL conversation were gathered using the survey adapted from the Ariadne Labs. The education presentation included a PowerPoint presentation, watching a video that discuss different ways of communicating EOL care, role playing, explaining how to use the Serious Illness Care Guide, and discussing case studies towards the end. Participants were given opportunities to ask questions during the presentation. The pretests were brief, anonymous, and were linked by a nickname that was created by participants in the beginning of the presentation. A posttest survey which is similar to the pretest was given to the participants right after the presentation and anonymously linked by a nickname created by participants during the pretest. A $10 gift card from Starbucks was given to anyone who participated in the project. The source of funding came from the personal funds of the author.

Outcome Measures

Sociodemographic information was collected using a form created by this author. At baseline or pre-data assessment, gender, profession, age, and zip code were recorded in the demographic survey. The pre and post survey tool utilized for the project was the Communication in Serious Illness Training Evaluation which was adopted from the Ariadne Labs. The Communication in Serious Illness Training Evaluation consisted of six survey sections (A to F):

1. Section A – course content evaluation.
2. Section B – course training evaluation.
3. Section C – skills self-assessment.
4. Section D – evaluation of trainer.
5. Section E – open-ended evaluation questions.
6. Section F – demographic survey.

This project adopted two sections from the instrument, which were section A and section C. Section C contains seven questions that were based on: (1) setting up the conversation, (2) assessing the patient's illness understanding, (3) sharing prognosis, (4) acknowledging and responding to patient's emotions, (5) exploring key topics and goals of the patient, (6) inquiring about fears and worries for future care, and (7) ability to speak less than 50% of the time

(Ariadne Labs, n.d.). A five-point Likert-type scale was used to facilitate data entry and statistical analysis. Each question is in a format of five possible answers ranging from 1 (not skilled at all) to 5 (Extremely skilled). All seven-item scores were added to yield a summary score of 5 to 35 points; a lower score indicated low skills and a higher score indicated high skills in EOL discussions.

A project evaluation survey was also included during the posttest implementation of the SICP to evaluate the effectiveness and impact of the education presentation. The project evaluation survey was composed of seven questions with a four-point Likert-type scale ranging from 4 (fully understand) to 1 (Not at all).

Validity and Reliability of Instruments

The Communication in Serious Illness Training Evaluation survey was developed in the U.S. by Ariadne Labs to assess attitudes, confidence, and acceptability of the SICP (Bernacki et al., 2015). The survey was created and designed by a team of palliative care experts at Ariadne Labs to complement the implementation of the SICP (Ariadne Labs, n.d.). Ariadne Labs is a joint center of Brigham and Women's Hospital and the Harvard School of Public Health which aims to promote innovation that will foster better care and optimal health in the U.S. (Ariadne Labs, n.d.). The evaluation survey included pre and post intervention self-assessment level of skill questionnaire. While this survey had not undergone validity and reliability testing, the survey had been used in various research that utilized SICP as the primary intervention (Bernacki et al., 2015). At this time, there is not enough evidence in the literature to suggest the Cronbach's alpha for this survey. The measurable outcome for this project included provider's skills and attitudes in EOL communication. This outcome may provide insights to the effectiveness of

SICP in improving clinicians' skills in discussing EOL care, thus contributing to future quality improvement in various healthcare settings, most especially in the primary care setting.

Data Analysis and Data Collection

SPSS was used for analysis and coding of data. Statistic mentor collaborated with the author in the selection of the appropriate statistical analysis. Descriptive statistical analysis was utilized to describe the sample characteristics and examine the distribution of variables. Also, due to the small sample size and the assumption of a non-normal distribution, a non-parametric test was used. Wilcoxon Signed-Rank test was utilized to compare the pretest and posttest data, while Pearson correlation coefficient was used to calculate the effect size where small effect size is 0.1, medium effect size is 0.3, and large effect size is 0.8.

Proposed Budget

The main costs for this project came from the printed materials and gift cards handed to the participants as a sign of appreciation for their attendance. A $10 gift card from Starbucks was given to the participants. The source of the fund came from the personal funds of the author. The estimated total costs to implement the project was $130.

Results

Sample Characteristics

A total number of 11 participants participated in the project which composed of 63.6% female and 36.4% male. About 63% of the participants identified themselves as White/Caucasian. The participants identified their area of discipline as nurse practitioners (54.5%), licensed social workers (27.3%), and registered nurses (18.2%). The age range of the participants was from age 30-39 (45.5%), age 40-49 (36.3%), and age 18-29 (18.2%). There was also a wide geographical variation among all the participants, as there was only two identical zip codes noted in the descriptive data.

Perceived Skills in End-of-Life Communication/Outcome variable

All seven questions from the pretest and posttest surveys showed statically significant results. The mean pre-intervention total score for all seven questions was 21.73 (SD = 3.58). The mean post-intervention total score for all seven questions was 27.36 (SD = 3.32). The Wilcoxon Signed-Rank test showed that a two-and-a-half-hour SICP education intervention elicited a statistically significant change in improving EOL communication skills of primary care providers (Z = -2.950, p = .003) with a large effect size (r = -0.62) which also suggested large clinical significance. Each question was also independently evaluated to show specific statistical results.

1. Setup a serious illness conversation – The mean pre-intervention score for this question was 2.91 (SD = 0.70) (1 = not at all skilled, 2 = somewhat skilled, 3 = skilled, 4 = very skilled, and 5 = extremely skilled). The mean post intervention score for this question was 3.82 (SD = 0.50). Wilcoxon Signed Ranks test indicated that the change from pre-test to post-test scores (Z = -2.887, p=0.004) was statistically significant.
2. Assess patient understanding of their illness - The mean pre-intervention score for this question was 3.27 (SD = 0.64) (1 = not at all skilled, 2 = somewhat skilled, 3 = skilled, 4 = very skilled, and 5 = extremely skilled). The mean post intervention score for this question was 3.91 (SD = 0.539). Wilcoxon Signed Ranks test indicated that the change from pre-test to post-test scores (Z = -2.333, p=0.020) was statistically significant.
3. Share prognosis - The mean pre-intervention score for this question was 3.27 (SD = 0.90) (1 = not at all skilled, 2 = somewhat skilled, 3 = skilled, 4 = very skilled, and 5 =

extremely skilled). The mean post intervention score for this question was 3.82 (SD = 0.75). Wilcoxon Signed Ranks test indicated that the change from pre-test to post-test scores (Z = -2.449, p=0.014) was statistically significant.

4. Acknowledge and respond to patient emotion - The mean pre-intervention score for this question was 3.18 (SD = 0.60) (1 = not at all skilled, 2 = somewhat skilled, 3 = skilled, 4 = very skilled, and 5 = extremely skilled). The mean post intervention score for this question is 4.18 (SD = 0.60). Wilcoxon Signed Ranks test indicated that the change from pre-test to post-test scores (Z = -2.810, p=0.005) was statistically significant.
5. Explore goals and inquire about fears and worries for future care - The mean pre-intervention score for this question was 3.09 (SD = 0.83) (1 = not at all skilled, 2 = somewhat skilled, 3 = skilled, 4 = very skilled, and 5 = extremely skilled). The mean post intervention score for this question was 4.18 (SD = 0.60). Wilcoxon Signed Ranks test indicated that the change from pre-test to post-test scores (Z = -2.111, p=0.035) was statistically significant.
6. Explore views on tradeoffs and inquire about views on critical abilities - The mean pre-intervention score for this question was 2.64 (SD = 0.67) (1 = not at all skilled, 2 = somewhat skilled, 3 = skilled, 4 = very skilled, and 5 = extremely skilled). The mean post intervention score for this question was 3.64 (SD = 0.67). Wilcoxon Signed Ranks test indicated that the change from pre-test to post-test scores (Z = -2.810, p=0.005) was statistically significant.
7. Speak <50% of the time - The mean pre-intervention score for this question was 3.36 (SD = 0.92) (1 = not at all skilled, 2 = somewhat skilled, 3 = skilled, 4 = very skilled, and 5 = extremely skilled). The mean post intervention score for this question was 4.27 (SD =

0.78). Wilcoxon Signed Ranks test indicated that the change from pre-test to post-test scores (Z = -2.428, p=0.015) was statistically significant.

Project Evaluation

All participants responded to the project evaluation survey which consisted of seven questions with scores ranging from 7 (lowest) to 28 (highest). All 11 participants only selected between 3 (Mostly) and 4 (Fully) from the Likert-type scale (1 – not at all, 2 – somewhat, 3 – mostly, and 4 – fully). The mean total score of the project evaluation was 26.4 (SD = 1.80). With that, participants found that the SICP presentation is beneficial and effective.

Discussion

The findings from this project showed that a two-and-a-half-hour education session may improve the skills of healthcare providers in EOL care discussion. Implementing the SICP in non-palliative healthcare setting, such as the primary care, can improve skills of clinicians in delivering EOL care. In addition, the benefit of this project for primary care providers were the increase in confidence in initiating EOL care conversation and identifying patients who may benefit from EOL discussions.

Based on the literature, primary care providers are in a better position to start EOL conversations because of the trusted relationship that they have with their patients. As a result, one of the potential long-term implications of this project is to improve the quality of life of patients who are being seen by clinicians who had the SICP training.

This project focused on bringing about a practice-changing knowledge in EOL care. EOL care that is rooted from the PEOL theory can provide concepts that can be used in different clinical settings. Also, incorporating the use of an evidence-based model of change could assist in a successful formulation and implementation of a proposed intervention. The two-and-a-half-hour SICP can also be implemented in various healthcare settings to provide a systematic impact to the community.

Findings from this project may be generalized but it should be noted that there wereonly 11 participants for this project. In addition, SICP is meant to be done in a group setting with more than one participant. This project met with participants and implemented the project in a one-on-one education setting. As a result, it may affect the generalizability of the findings. Despite that, a one education session showed statistically significant changes in the skills of the participants.

Conclusion/Summary

For healthcare providers, as well as for patients and their families, EOL care presents many challenges. This evidence-based project demonstrated that implementing a short and brief education session such as the SICP can improve the skills of non-palliative healthcare providers in end-of-life communication. The literature suggests that early and effective EOL conversations can benefit both patients and healthcare providers. For patients, early and better EOL care discussions ensure that their wishes and values are being heard, thus resulting in a better quality of life. Healthcare providers can foster trust with their patients as they are focusing on the patients' goals and priorities. Using the SICP as an educational tool can promote more EOL conversations, which may also result in reducing unwanted hospitalizations, promoting a peaceful death, and avoiding confusion about the preferences of care when patients are not able to make decisions for themselves. The implementation of this project may increase the confidence and comfort of primary healthcare providers in engaging in EOL care discussions. Thus, patients who may be nearing the end of life can have earlier and better conversations about their goals, wishes, and values that will inform their future care

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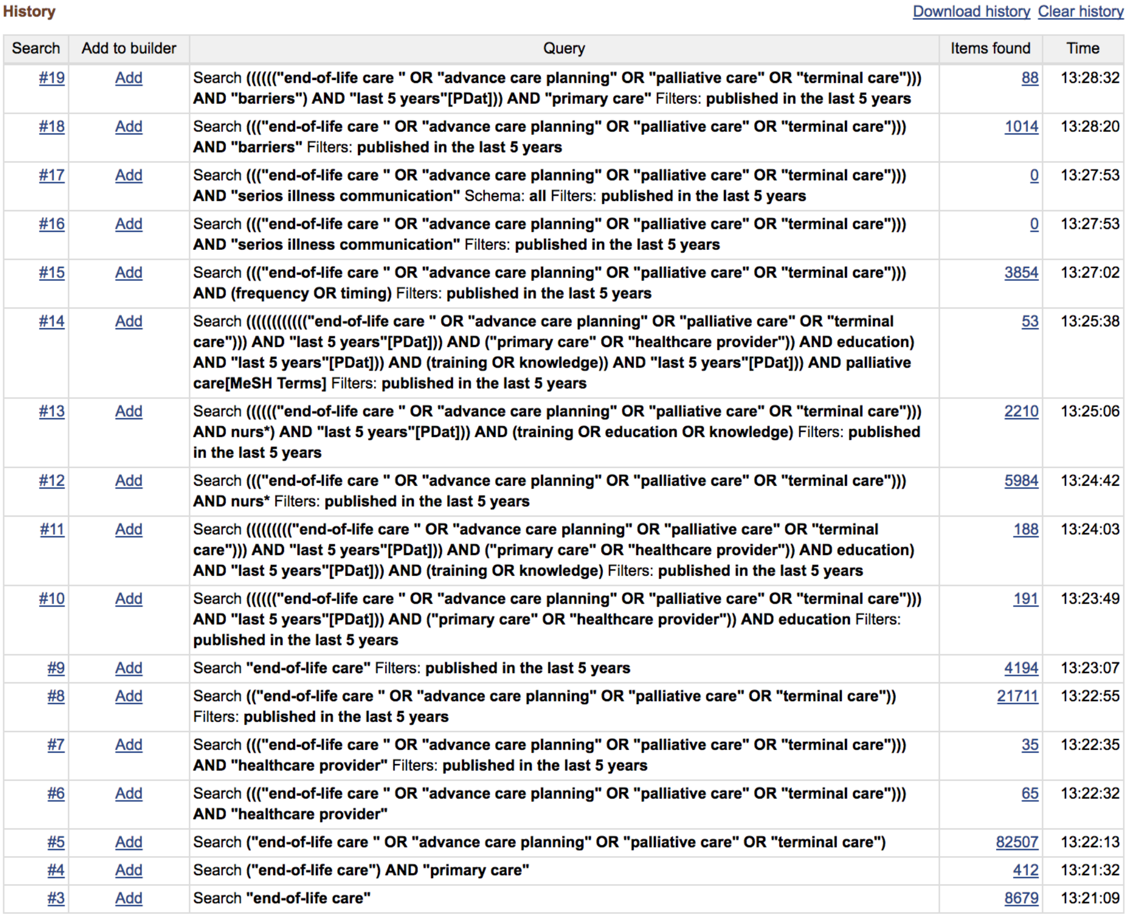
Appendix A

Databases

Figure 1. PubMed Database



Search	Add to builder	Query	Items found	Time
#19	Add	Search **((((((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "barriers") AND "last 5 years"[PDat])) AND "primary care"** Filters: **published in the last 5 years**	88	13:28:32
#18	Add	Search **((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "barriers"** Filters: **published in the last 5 years**	1014	13:28:20
#17	Add	Search **((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "serios illness communication"** Schema: **all** Filters: **published in the last 5 years**	0	13:27:53
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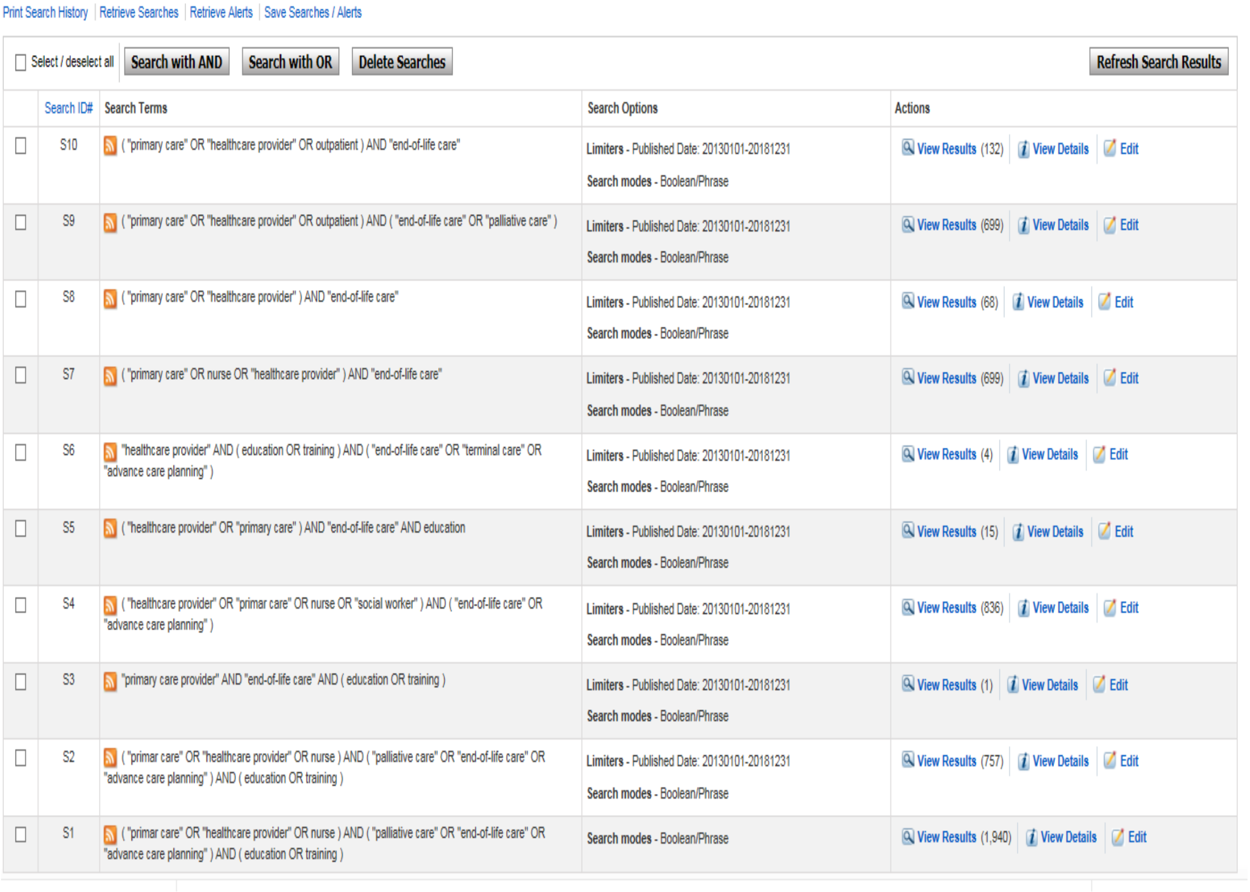
#15	Add	Search **((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND (frequency OR timing)** Filters: **published in the last 5 years**	3854	13:27:02
#14	Add	Search **(((((((((((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "last 5 years"[PDat])) AND ("primary care" OR "healthcare provider")) AND education) AND "last 5 years"[PDat])) AND (training OR knowledge)) AND "last 5 years"[PDat])) AND palliative care[MeSH Terms]** Filters: **published in the last 5 years**	53	13:25:38
#13	Add	Search **(((((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND nurs*) AND "last 5 years"[PDat])) AND (training OR education OR knowledge)** Filters: **published in the last 5 years**	2210	13:25:06
#12	Add	Search **((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND nurs*** Filters: **published in the last 5 years**	5984	13:24:42
#11	Add	Search **((((((((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "last 5 years"[PDat])) AND ("primary care" OR "healthcare provider")) AND education) AND "last 5 years"[PDat])) AND (training OR knowledge)** Filters: **published in the last 5 years**	188	13:24:03
#10	Add	Search **(((((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "last 5 years"[PDat])) AND ("primary care" OR "healthcare provider")) AND education** Filters: **published in the last 5 years**	191	13:23:49
#9	Add	Search **"end-of-life care"** Filters: **published in the last 5 years**	4194	13:23:07
#8	Add	Search **(("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))** Filters: **published in the last 5 years**	21711	13:22:55
#7	Add	Search **((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "healthcare provider"** Filters: **published in the last 5 years**	35	13:22:35
#6	Add	Search **((("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care"))) AND "healthcare provider"**	65	13:22:32
#5	Add	Search **("end-of-life care " OR "advance care planning" OR "palliative care" OR "terminal care")**	82507	13:22:13
#4	Add	Search **("end-of-life care") AND "primary care"**	412	13:21:32
#3	Add	Search **"end-of-life care"**	8679	13:21:09

Appendix B

Databases

Figure 2. Cumulative Index of Nursing and Allied Health Literature (CINAHL) Database



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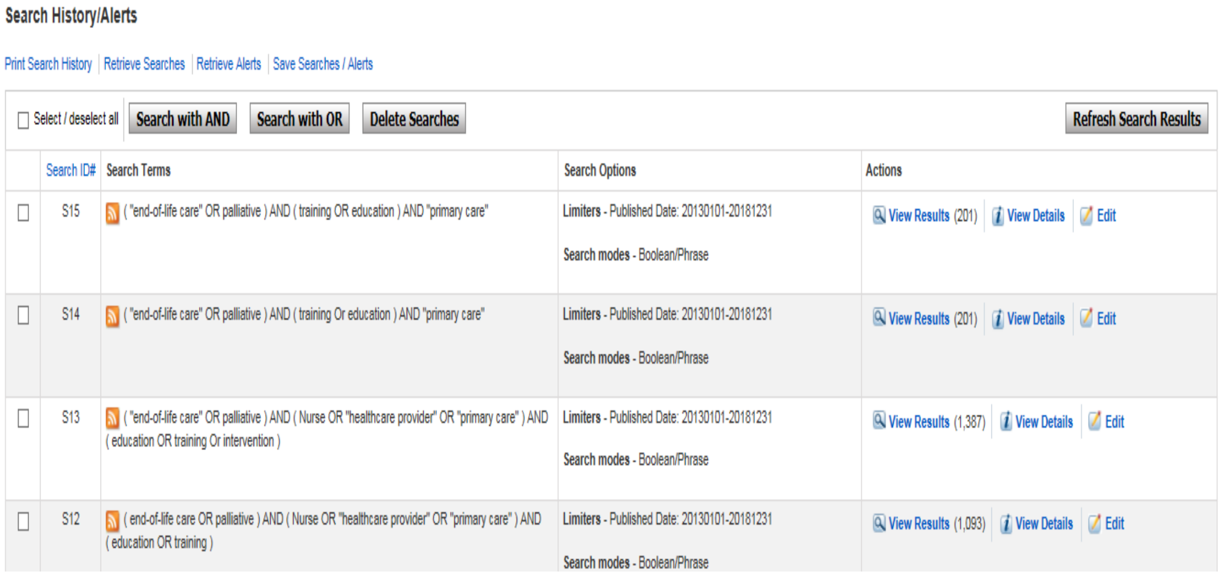
☐	S10	("primary care" OR "healthcare provider" OR outpatient) AND "end-of-life care"	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (132) | View Details | Edit
☐	S9	("primary care" OR "healthcare provider" OR outpatient) AND ("end-of-life care" OR "palliative care")	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (699) | View Details | Edit
☐	S8	("primary care" OR "healthcare provider") AND "end-of-life care"	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (68) | View Details | Edit
☐	S7	("primary care" OR nurse OR "healthcare provider") AND "end-of-life care"	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (699) | View Details | Edit
☐	S6	"healthcare provider" AND (education OR training) AND ("end-of-life care" OR "terminal care" OR "advance care planning")	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (4) | View Details | Edit
☐	S5	("healthcare provider" OR "primary care") AND "end-of-life care" AND education	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (15) | View Details | Edit
☐	S4	("healthcare provider" OR "primar care" OR nurse OR "social worker") AND ("end-of-life care" OR "advance care planning")	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (836) | View Details | Edit
☐	S3	"primary care provider" AND "end-of-life care" AND (education OR training)	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (1) | View Details | Edit
☐	S2	("primar care" OR "healthcare provider" OR nurse) AND ("palliative care" OR "end-of-life care" OR "advance care planning") AND (education OR training)	Limiters - Published Date: 20130101-20181231 Search modes - Boolean/Phrase	View Results (757) | View Details | Edit
☐	S1	("primar care" OR "healthcare provider" OR nurse) AND ("palliative care" OR "end-of-life care" OR "advance care planning") AND (education OR training)	Search modes - Boolean/Phrase	View Results (1,940) | View Details | Edit

Appendix C

Databases

Figure 3. Academic Search Premier Database

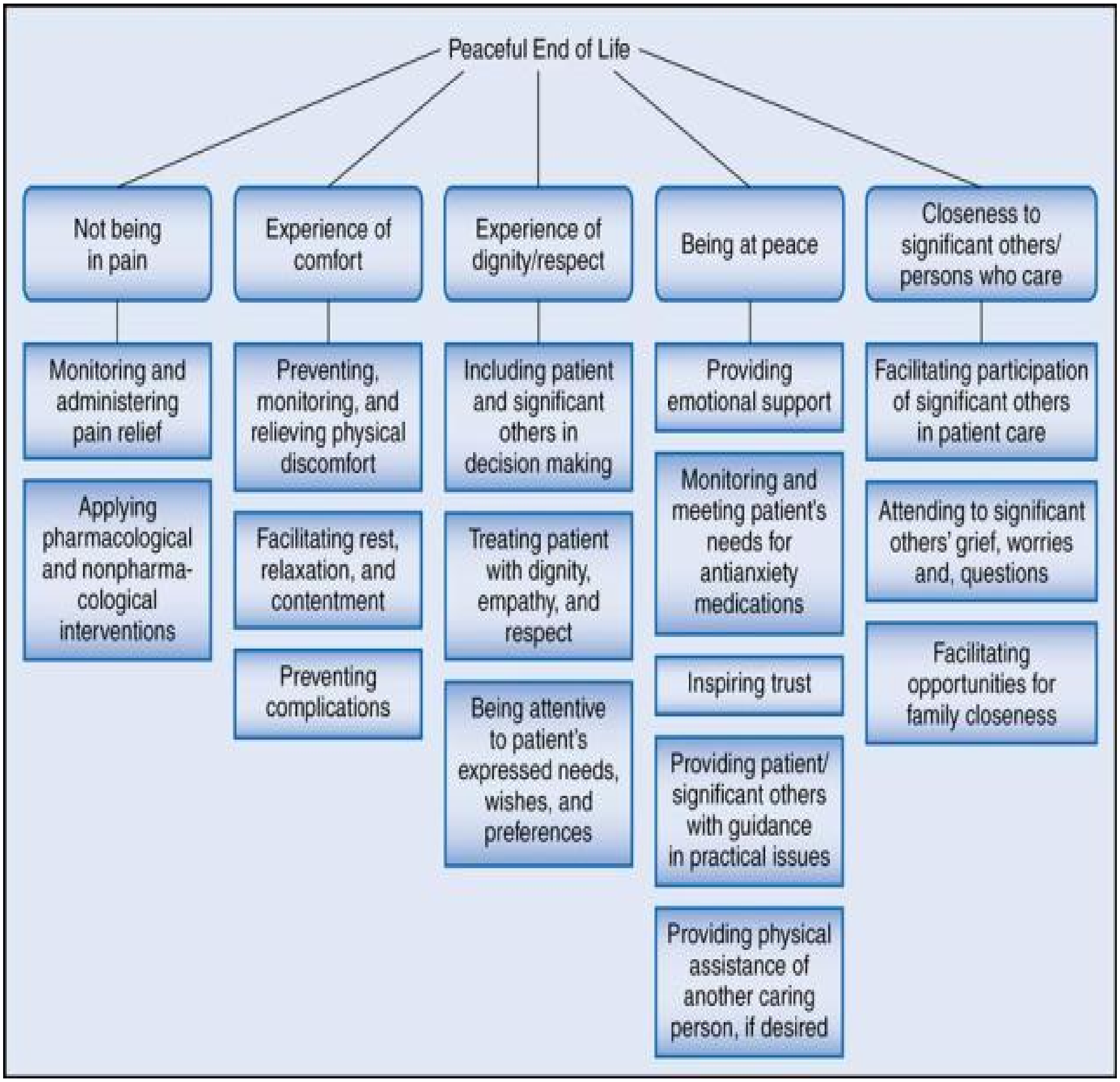


	Search ID#	Search Terms	Search Options	Actions
☐	S15	("end-of-life care" OR palliative) AND (training OR education) AND "primary care"	**Limiters** - Published Date: 20130101-20181231 **Search modes** - Boolean/Phrase	View Results (201) | View Details | Edit
☐	S14	("end-of-life care" OR palliative) AND (training Or education) AND "primary care"	**Limiters** - Published Date: 20130101-20181231 **Search modes** - Boolean/Phrase	View Results (201) | View Details | Edit
☐	S13	("end-of-life care" OR palliative) AND (Nurse OR "healthcare provider" OR "primary care") AND (education OR training Or intervention)	**Limiters** - Published Date: 20130101-20181231 **Search modes** - Boolean/Phrase	View Results (1,387) | View Details | Edit
☐	S12	(end-of-life care OR palliative) AND (Nurse OR "healthcare provider" OR "primary care") AND (education OR training)	**Limiters** - Published Date: 20130101-20181231 **Search modes** - Boolean/Phrase	View Results (1,093) | View Details | Edit

Appendix D

Tables and Figures

Figure 4. Peaceful End of Life Theory

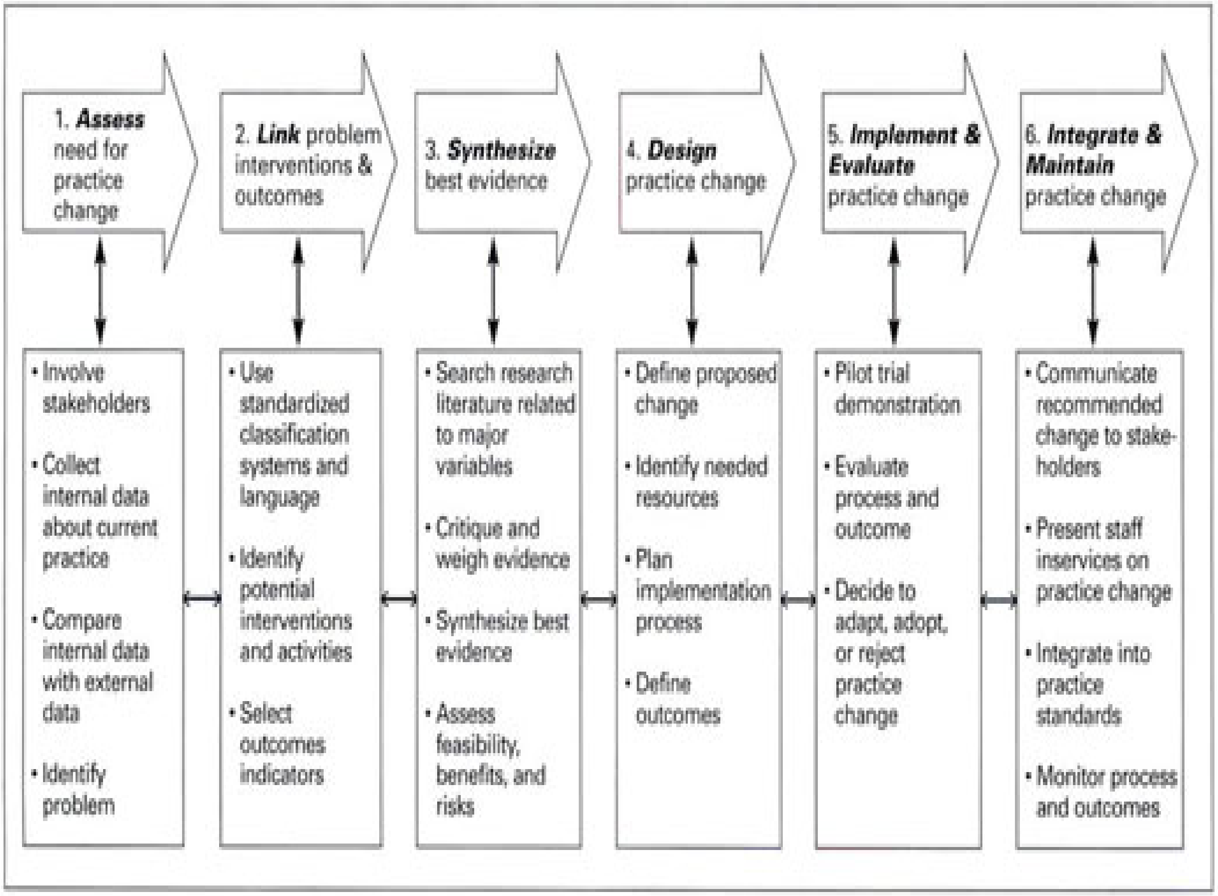


Appendix E

Tables and Figures

Figure 5. Rosswurm and Larrabee Model

Figure 2.
A Model for Evidence-Based Practice Change



Source: Rosswurm & Larabee, 1999.

Appendix F

Evaluation Table

Table 1. Evaluation Table: End-of-Life Care

Citation	Conceptual Framework	Design/ Method/ Sampling (Grounded Theory, phenomenology, Narrative…)	Sample/Setting (describe)	Major Variables Studied and Their Definitions	Measurement / Instrumentation (focus group, 1:1, researcher(s)	Data Analysis	Findings/ Themes	Level/Quality of Evidence; Decision for practice/ application to practice/ Generalization
Raphael, Deborah, Waterworth, Susan, & Gott, Merryn. (2014). The role of practice nurses in providing palliative and end-of-life care to older patients with long-term conditions. *International Journal of Palliative Nursing, 20*(8), 373-379. **Country:** NZ **Funding:** NZ Heart Foundation and the Grace Craston Charitable Trust.	Humanistic Model	**Design:** QDS/ Purposive sampling **Purpose:** To explore the role of nurses in providing EOLC to older pts with LCs	N - 21 PCNs **Demographic:**Age – 20-30 y/o 4.8%, 31-40 y/o 28.6%, 41-50 y/o 23.8%, 51-60 42.8% Ethnicity NZ 71.4%, Maori 14.3%, European 9.5%, Indian 4.8% **Setting**: Urban and rural areas of NZ **Inclusion:** PGS in LC	IV: what is the role of nurses in providing EOLC in pts with LC DV1:Experience of providing EOL and ACP DV2:Education and training EOL care DV3:Enablers or key barriers in providing EOL care	SSI by telephone and audio recorded	Qualitative Thematic analysis	DV1:There is a variability in the involvement of PCN in EOLC DV2: Most PCNs have limited training and education in EOLC DV3: PCNs have more time to spend with pts than GP, 50% feel the need to hand pts to palliative	**LOE:** VI **S:** focus on PCN, wide variety of locations **W:** mostly f, only PGS nurses, sample bias **C:** Priority should be given to developing the palliative care skills and knowledge of PCNs **F:** Substantiates the need in improving knowledge of

Key: **AA**- african american **AC**- acute care; **ACP-** advance care planning; **a**- alpha; **C**- conclusion; **CARES-MIS**- cancer rehabilitation evaluation system medical interaction subscale; **CC**- critical care; **CI**- confidence interval; **CRCT**- cluster randomized controlled trial; **CS**- convenience sampling; **CST**- communication skills training; **DCS**- decision conflict scale; **DMC**- decision making confidence **DV**-dependent variable; **EOL**- end of life; **EOLC**- end of life care; **ESAS**- Edmonton symptom assessment system; **F**- feasibility; **FACIT-sp**- functional assessment of chronic illness therapy; **FAMCARE-P16**- patient satisfaction with care measures; **f**- female; **GP**- general practitioner; **HADS**- hospital anxiety depression scale; **HCA**- healthcare assistant; **HCE**- healthcare experience; **HF**- heart failure; **IM**- internal medicine **IV**- independent variable; **LC**- long-term condition; **LOE**- level of evidence; **M**-mean; **ME**- middle eastern; **MP**- midlevel provider; **MTG**- medical training graduate; **m**- male; **N**-number of studies; **NM**- nurse manager; **NR**- none reported; **NS**- non-significant; **NZ**- new zealand; **NYHA**- new york heart association; **n**- number of participants; **OR**- odds ratio **PC**- primary care; **PCN**- primary care nurse; **PD**- pediatrics; **PPD**- pretest posttest design; **PGS**- post-graduate study; **PS**- purposive sampling; **PTSS**- post-traumatic stress symptoms**;** **p**- physician; **pts**- patients; **QES**- qualitative exploratory study; **QN**- qualified nurse; **QDCS**; qualitative descriptive and comparative study; **QDS**- qualitative descriptive study; **QOC**- quality of end-of-life communication; **QUAL**-E- quality of life at the end of life scale; **RCT**- randomized controlled trial; **RGCP**- royal college of general practitioners; **S**- strengths; **SEPC**- self-efficacy in palliative care**;** **SCT**- social cognitive theory; **SICP**- serious illness care program; **SIP**- seriously ill patients; **SPIRIT**- sharing patient's illness representations to Increase Trust; **SSI**- semi-structured interview; **SQ**- surprise question **T**- time; **TEOLC**- transforming end of life care; **TFAT**- team functioning assessment tool; **UC**- urgent care; **UK**- united kingdom; **W**- weakness: **WNH**- white non-hispanic; **YOE**- years of experience

Citation	Conceptual Framework	Design/ Method/ Sampling (Grounded Theory, phenomenology, Narrative…)	Sample/Setting (describe)	Major Variables Studied and Their Definitions	Measurement / Instrumentation (focus group, 1:1, researcher(s)	Data Analysis	Findings/ Themes	Level/Quality of Evidence; Decision for practice/ application to practice/ Generalization
Bias: NR			**Exclusion:** NR **Attrition:** 0				specialists	PCNs in EOLC. PCNs are also helpful in increasing the discussion of EOL

Citation	Conceptual Framework	Design/ Method/ Sampling (Grounded Theory, phenomenology, Narrative…)	Sample/Setting (describe)	Major Variables Studied and Their Definitions	Measurement / Instrumentation (focus group, 1:1, open-ended survey)	Data Analysis	Findings/ Themes	Level/Quality of Evidence; Decision for practice/ application to practice/ Generalization
Mitchell, S., Loew, J., Millington-Sanders, C., & Dale, J. (2016). Providing end-of-life care in general practice: Findings of a national GP questionnaire	Humanistic model	**Design:** Mixed Method Study **Purpose:** To provide insight into	N – 516 GPs **Demographic:** Experience in general practice: <5 yrs, 79 (15.4%), 5-10 yrs 79	IV – Insights into the experience of GPs providing EOLC in the community, particularly the barriers to good-	Online questionnaire survey with a total of 26 questions with opportunity	Data were coded independently by two researchers Free-text data were	DV1-Continuity of care was identified as being of vital importance in the provision of EOLC in	**LOE:** VI **S:** large sample, sample all across the UK **W:** lack of demographic

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survey. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners, 66*(650), E647-53. **Country:** UK **Funding:** RCGP/Marie Curie End-of-Life Care Clinical Priority Workstream of the RGCP Clinical Innovation and Research Centre **Bias:** None		the experience of GPs providing EOLC in the community, particularly the facilitators and barriers to good-quality care.	(15.4%), >10 354 (69.1%), not stated 4 (0.8%) = 516 **Setting:** A web-based national UK questionnaire survey circulated via the RGCP to GPs. **Inclusion:**GPs **Exclusion:**NR **Attrition:**0	quality care DV1- Continuity of care DV2- Patient and family factors DV3- Expertise and training DV4- Medical management.	for free-text	coded using NVivo 10 software (version 10)	primary care. Only 122 out of 492 (24.8%) responders stated that they always had the chance to discuss EOLC wishes with patients DV2-Key factors concerning patients and families included opportunity for care planning discussions DV3-GPs, 19 out of 513 (3.7%) stated that they had	information, use of questionnaire as instrumentation **C:** there is a challenge in identifying pts who are in need of palliative care, ongoing need for training or education for PC providers. **F:** Need for more effective communication and training for GPs to have better EOLC in the community.

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							had no training in the delivery of EOLC, and 112 out of 513 (21.8%) stated they had received inadequate training. Adequate training was reported by 321 out of 513 (62.6%) responders. The remaining 61 participants (11.9%) answered ‘other’ to this question and provided free-text details, highlighting particularly the need to actively seek out training	

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							courses in EOLC DV4 – inadequate symptom control were identified.	

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Nedjat-Haiem, F., Carrion, I., Gonzalez, K., Ell, K., Thompson, B., & Mishra, S. (2017). Exploring Health Care Providers' Views About Initiating End-of-Life Care Communication. *American Journal of Hospice*	Humanistic model	**Design:** QES/stratified PS **Purpose:** To examine perceptions of both medical & non-medical	N -79 **Demographic:** p 31.6%, Nurse 29.1%, SW 21.5%, & chaplain 17.7%. m 43% / f 57%. AA 11%, Asian 13%, WNH 44%, Latino 24%, Indian	IV – Roles and responsibilities for initiating EOLC with SIP DV1– Providers' roles in engaging in EOLC DV2- The	Audio-recorded transcribed interviews	Qualitative content analysis	DV1- There is a great variability in the roles of medical and non-medical providers in engaging in EOLC discussions. Some deemed	**LOE:** VI **S:** Includes various medical and non-medical providers, sample diversity **W:** sample from only 2 medical centers **F:** Substantiates the need for

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and Palliative Medicine®, 34(4), 308-317. **Country:** USA **Funding:** American Cancer Society Doctoral Training Grants in Oncology Social Work And US Department of Veterans Affairs, Hartford/VA Social Work Scholars Program. **Bias:** None		provider's roles and responsibilities for initiating EOLC communication with SIP and their families	3%, ME 5% . HCE w/ more than 20 y 28%, 11 to 20 y 24%, 5 to 10 y 33%, 1 to 4 y 13%, <1 y 2%. **Setting:** 2 medical centers in Los Angeles, California **Inclusion:** Some clinical experience working with seriously ill patients with cancer and their families. **Exclusion:** NR **Attrition:** 0	responsibility of physicians for initiating and leading discussions DV3- The need for team co-management in pts care			that it is not their responsibility and some think it is their responsibility SW (71%) & chaplain (86%). DV2- 87% of providers said EOLC is the physicians responsibility. DV3- It was reported that working as a team was an essential part of communication because it encourages dialogue across disciplines	educating both non-medical and medical HCP in EOLC discussions and their role. Collaborative approach is more desired and it can increase frequency of EOLC discussions

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Selman, Lucy. (2016). Improving confidence and competence of healthcare professionals in end-of-life care: An evaluation of the 'Transforming End of Life Care' course at an acute hospital trust. *Supportive & Palliative Care, 6*(0), 231-237. **Country:** UK **Funding:** Health Education South	Comskil model	**Design:** Mixed-method longitudinal approach Surveys & Interviews **Purpose:** To evaluate course participants' self-rated confidence, competence and	N – 236 healthcare workers **Demographics:** 49.2% QN, 16.1% NM, 15.3% GP, 5.5% HCA, 5.1% MTG, 9% other Health care personnel. 41.9% work at the hospital & 54.7% in the community **Setting:** Hospital and community clinics in the UK	IV- 2-day TEOLC course **Quantitative** DV1- S 14 self-assessment questions examined confidence, understanding and knowledge of EOLC topics **Qualitative** DV2-confidence in practice DV3-confidence in	SEPC 10-point Likert scale (0=very anxious and 10=very confident). SSI 20 minutes	Mean change scores and paired t tests were calculated and free-text responses analysed thematically	**Quantitative:** DV1:Significant improvement ($p<0.001$) was identified in all self-assessment topics **Qualitative:** DV2- participants are more likely and have more desire to engage in EOLC discussions	**LOE:** **S:** Mixed method **W:** Sampling process not clearly defined **C:** The TEOLC course improved participants' self-rated confidence, competence and knowledge in EOLC. **F:** Educational

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London's Strategic Programmes grant to King's Health Partners **Bias:** None		knowledge of EOLC topics.	**Inclusion:**NR **Exclusion:**NR **Attrition:**0	education			DV3- Participants would recommend the course and reported that it would influence their practice	intervention is effective in improving confidence of healthcare providers in providing EOL care and it is highly accepted by HCP
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		phenomenology, Narrative…)			1:1, open-ended survey)			practice/ Generalization
Coyle, N., Manna, R., Shen, M., Banerjee, S., Penn, S., Pehrson, C., . . . Bylund, C. (2015). Discussing Death, Dying, and End-of-Life Goals of Care: A Communication Skills Training Module for Oncology Nurses. *Clinical Journal of Oncology Nursing, 19*(6), 697-702. **Country:** USA **Funding:** Geri and ME Fund, Memorial Sloan Kettering Nursing Education, the Fridolin Charitable Trust, and the National Cancer Institute	Comskil Model	**Design:** Retrospective study PPD/Convenience sampling **Purpose:** To adapt EOLC CST module and evaluate confidence and skills of the participants and satisfaction with the module	n= 247 nurses working in oncology **Demographics:** AC – 68% PC – 16% CC -10% UC – 6% **Setting:** Inpatient oncology **Inclusion:** Nurses working in oncology and participated in CST **Exclusion:** None reported **Attrition:** 0	IV- EOL CST module; a 45 minute didactic and 90 minute of small group interaction DV1 - confidence in discussing death, dying, and end-of-life goals of care with patients, DV2 - Overall satisfaction with the module	Ordinal, five-point Likert-type scales	Paired-sample T-test	1–5 Likert-type scale when compared before (— X = 3.09, SD = 1.03) and after (— X = 4.07, SD = 0.69) they attended the module (t246 = -18.66, p<0.001)	**LOE:** III **S:** Solid framework, large n size **W:** Non-RCT, CS, exclusion for participants not reported, no blinding, single hospital **C:** Significant increased in confidence on discussing death, dying, and EOL goals of care with pts, as well as overall satisfaction with the module **F:** Proves that education can improve

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Bias: None								confidence and knowledge of nurses in EOLC communication

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Lakin, J., Koritsanszky, L., Cunningham, R., Maloney, F., Neal, B., Paladino, J., . . . Bernacki, R. (2017). A Systematic Intervention To Improve Serious Illness Communication In Primary Care. *Health Affairs (Project Hope), 36*(7), 1258-1264. **Country:** USA	Comskil model	**Design:** Prospective Cohort Implementation Trial/CS **Purpose:** To evaluate the use of SICP in a high-risk PC population on the prevalence, timing,	N - 178 IG - 101 CG - 77 **Demographic:** 50.6% are m, M age is 79, WNH 80.2% **Setting:** 14 PC clinics IG-6 CG-8	IV- SICP DV1- prevalence, timing, & accessibility of conversations DV2- comprehensiveness of conversation DV3- frequency of screening **Time frame:** 24	Retrospective chart review Likert Scale	T-tests	pts in the IG (62.4%) than in the CG (42.9 %; p ¼ 0.0020) had documentation of at least one serious illness conversation. Comprehensiveness of conversation $p<0.0001$ timing NS – p =	**LOE:**II **S:** Blinding retrospective chart review, diverse clinics **W:** CS, lacked data on direct pts outcomes, SQ may prompt providers to initiate EOLC for CG

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Funding: Partners HealthCare and the Charina and Branta Foundations **Bias:** None		accessibility, and comprehensiveness of documented serious illness conversations & hospice use among pts.	**Inclusion:** pts that may die in the next 2 years based on the clinician SQ survey "Would you be surprised if this patient died in the next 2 years?" or based on clinicians' judgment **Exclusion:** None **Attrition:** 0	months			0.8197 Intervention clinics screened more pts (72.7 % compared to 39.6 % in comparison clinics; p ¼ 0:0005)	**C:** Improves access to high-quality serious illness conversations for PC pts in a high-risk care management program **F:** Brief clinician training may improve frequency and confidence of providers in EOLC.
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Hjelmfors, L., Van Der Wal, M., Friedrichsen, M., Mårtensson, J., Strömberg, A., & Jaarsma, T. (2015). Patient-Nurse Communication about Prognosis and End-of-Life Care. *Journal of Palliative Medicine,18*(10), 865-871. **Country:** Netherlands and Sweden **Funding:** Heart and Lung Foundation and King Gustaf V and Queen Victoria's Foundation of the Freemasons. **Bias:** NR	Humanistic model	**Design:** QDCS **Purpose:** To explore why and how often HF nurses discuss prognosis and EOL care.	N - 279 nurses N -1809 patient conversations **Demographics: HF nurses:** 90% f, M age 50, M YOE 27, YOE with HF pts 10. **HF pts: Sweden 611:** m – 68%, married/LWP 65%, Age M age 70 **HF pts Netherlands 1198:** m – 58%, M age 72, 88% are NYHA class II or III **Setting:** HF outpatient clinics	IV – Registration form and survey DV1 – Frequency discussing prognosis DV2 – Frequency discussing EOL care	Short registration form for every HF patient they met in their practice during a pre-specified week. Open-ended questions about EOL care and prognosis conversations.	Student's t-tests and chi-square tests.	DV1-Prognosis was discussed in 687 patients (38%) DV2-EOL care only 179 patients (17%), 1060 patients (62%) with whom prognosis was not discussed, nurses reported that this could be relevant to discuss in the future in 70% of the patients. Prognosis was more often discussed with the Dutch patients	**LOE-** VI **S -** large sample size for qualitative study **W-** instrumentation, survey form was used instead of interviews. **C-** Patient-nurse communication about prognosis and end-of-life care does not seem to be routine in patient education in HF clinics, and these discussions could be included more often. **F-** Even in specialized clinics, EOLC is lacking, therefore the need

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			Inclusions: HF nurses **Exclusion:** NR **Attrition:**19.5%				compared to the patients in Sweden (41% versus 34%, p < 0.001); a significant difference was also seen in conversations about end-of-life care (13% versus 4%, p < 0.001)	for educating healthcare providers is critical
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Song, Ward, Fine, Hanson, Lin, Hladik, . . . Bridgman. (2015). Advance Care Planning	Social Cognitive Theory SCT	**Design:** 2 group RCT **Purpose:** To	N - 210 IG - 109 CG - 101	IV - SPIRIT intervention included 2 sessions, and all sessions	TFAT, DCS, DMC (a = 0.74), HADS-	OR CI P value	Patient Decisional Conflict Scale scores decreased	**LOE:** II **S:** randomization, low risk, low cost **W:** Low sample

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and End-of-Life Decision Making in Dialysis: A Randomized Controlled Trial Targeting Patients and Their Surrogates. *American Journal of Kidney Diseases, 66*(5), 813-822. **Country:** USA **Funding:** National Institutes of Health, National Institute of Nursing **Bias:** NR		examine the efficacy of ACP on preparation for EOL decision making for dialysis pts and surrogates and for surrogate's bereavement outcomes	**Demographic:** Patient- M age is 62.6, 57% f, HSG 52.5% Surrogate - M age is 54.1, 72% is f, HSG 46.2% **Setting:** 20 outpatient dialysis centers **Inclusion:** 18 y/o or older, AA or white, on dialysis therapy at least 6 months, CCI score of 6 or CCI score of 5 and hospitalization in the last 6 months, English speaking for both surrogates and pts.	included both patient and surrogate. DV1 – pts and surrogate preparedness (baseline, 2, 6 , & 12 mos) DV2 – surrogate bereavement after death (baseline, 2, 6, & 12 mos) **Time frame**: 2 years	anxiety (a = .83), PTSS-10 (a = 0.89), HADS-depression (a = 0.56)		over time in SPIRIT while increasing in control, a significant intervention effect across time points (β = −0.12; 95% confidence interval [CI], −0.22 to −0.02; *P* = 0.01) DCS – OR/CI:−0.12 (−0.22 to −0.02) HADS anxiety – OR −1.2 (−2.8 to 0.3) PTSS-10 – OR/CI: −4.0 (−10.2 to 2.2) HADS-depression –	size **C:** SPIRIT was associated with improvements in dyad preparation for end-of-life decision making and surrogate bereavement outcomes **F:** SPIRIT or educating the patients about illness cognition has beneficial effect on patients and surrogates for EOL decision making. Therefore substantiating the need for healthcare providers to have the knowledge to engage in EOL discussions.

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			Exclusion: if not meet inclusion criteria **Attrition:** 13%				OR/CI: −2.54 (−4.34 to −0.74)	
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Zimmermann, Swami, Krzyzanowska, Hannon, Leighl, Oza, . . . Lo. (2014). Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial. *The Lancet, 383*(9930), 1721-1730. **Country:** Canada	Humanistic Model	**Design:** CRCT **Purpose:** To assess the effect of early palliative care in patients with advanced cancer on several aspects of QOL	N - 461 IG - 228 CG – 233 **Demographics:** **IG** M age 61.2, f 59.6% **CG** M age 60.2, f 53.6% **Setting:** Oncology clinics	IV: Consultation and follow up in the oncology palliative care clinic by RNs and physicians DV1: QOL DV2: Symptom severity DV3:Satisfaction with care DV4: Problems with medical	FACIT-sp (a = 0.86), QUAL-E, ESAS (a = 0.75), FAMCARE-P16, CARES-MIS scales	Mixed effects models, implemented with PROC MIXED or GLIMMIX using SAS software	FACIT-Sp at 3 months did not differ significantly between groups (mean change score in intervention group +1·60 [SD 14·46] *vs* control group −2·00 [13·56], p=0·07)	**LOE:** II **S**: randomization **W**: done at one center, interventions were not masked **C**: This study suggests that early palliative care might improve quality of life and increase satisfaction with

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Funding: Canadian Cancer Society, Ontario Ministry of Health and Long Term Care **Bias:** Done at one center, selection bias			**Inclusion:** 18 y/o and older, Stage IV cancer, estimated survival of 6-24 months **Exclusion:** Non-english speaking and inability to pass cognitive screening test **Attrition: NR**	interactions **Time frame** – 4 months			QUAL-E was significant (+2·33 [8·27] *vs* +0·06 [8·29], p=0·05) ESAS was not significant (+0·14 [16·93] *vs* +2·12 [13·88], p=0·33) The secondary 4-month endpoint, the differences in change scores were significant for FACIT-Sp (+2·46 [15·47] *vs* −3·95 [14·21], p=0·006), QUAL-E (+3·04 [8·33] *vs* −0·51	their care for patients with a large range of advanced solid tumor malignancies **F:** Early palliative or EOLC can have a positive impact on quality of life.

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							[7·62], p=0·003), and ESAS (−1·34 [15·98] *vs* +3·23 [13·93], p=0·05 At the 4-month endpoint, the significant differences for FACIT-Sp, QUAL-E, and FAMCARE-P16 were robust across analyses, whereas the significant difference for the ESAS was not	
Paladino, Lamas, Lakin, Epstein, & Bernacki. (2016). Delivering More, Better and Earlier Goals of Care Conversations to	Social Cognitive Theory	**Design:** CRCT **Purpose:** Evaluate	N1 (clinicians) 90 N2 (patients) 342 IG1 – 47 CG1- 43 IG2 – 176	IV – Systematic intervention includes: clinician identification of patients at high risk	EMR chart review	P value analysis	DV1- 342 patients enrolled: 176 intervention; 166 control;	**LOE:** II **S:** RCT **W:** Only preliminary data is available. Many

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Seriously Ill Oncology Patients in the Clinical Setting (FR481C). *Journal of Pain and Symptom Management, 51*(2), 380-381. **Country: USA** **Funding:** Not disclosed **Bias:** Site		clinician adoption and acceptability of the serious illness intervention. Determine the frequency, timing, and quality of goals-of-care documentation before death	CG2 -166 **Demographic:** Oncology clinicians Patients in Dana Farber Cancer Institute **Setting:** Cancer Institute **Inclusion:** Only preliminary data available, study still ongoing **Exclusion:** Only preliminary data available, study still ongoing **Attrition:** None reported	of death in a year using the ‘‘surprise’’ question; 21⁄2 hour clinician training on the Serious Illness Conversation Guide; email trigger/reminder; and EMR documentation DV1 – Frequency and timing of EOL discussions DV2 – Quality of EOL goals of care documentation			38% died (n=131). Among patients who died, preliminary chart review showed that more goals-of-care conversations were documented before death in intervention compared to control (92% versus 70%, p=0.0037); intervention conversations took place three months earlier than control (median 143 days versus 63 days,	components of the research method are missing and not explicitly reported. **C:** Preliminary data about the Serious Illness Care systematic approach demonstrated strong clinician adoption and acceptability. The intervention resulted in more, better, and earlier conversations and documentation about patient values and priorities in the medical record F: An effective and better

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							p=0.0008). DV2- conversations were more patient-centered (95% versus 45%, p<0.001) and more readily retrievable in the EMR (68% versus 28%, p<0.001).	communication between healthcare providers and pts can improve EOLC discussions and honor pts wishes and values.

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Appendix G

Summary Table

Table 2. Synthesis Table

Author	Paladino	Coyle	Hielmfors	Lakin	Mitchell	Nedjat-Hajem	Raphael	Selman	Song	Zimmermann
Year	2016	2015	2015	2017	2016	2017	2014	2016	2015	2014
Level of Evidence										
I										
II	x			x				x	x	x
III		x								
IV										
V										
VI			x		x	x	x			
Study Design										
Randomized Controlled Trial	x								x	x
Qualitative descriptive-comparative			x							
Mixed-method					x			x		
Prospective Cohort				x						
Retrospective-Pre/Post		x								
Qualitative descriptive-exploratory									x	
Qualitative descriptive							x			
Qualitative exploratory						x				x
Sample										
n	90(clinicians)/342 (patients)	247	279(clinicians)/1809 (patients)	178	516	79	259	236	210	410
Author	Paladino	Coyle	Hielmfors	Lakin	Mitchell	Nedjat-	Raphael	Selman	Song	Zimmermann

						Hajem				
Year	2012	2015	2015	2017	2016	2017	2014	2016	2015	2014
Patients' with chronic illnesses	x		x						x	x
Nursing (non-palliative)		x	x	x		x	x	x		
Social worker				x		x				
Chaplain						x				
Physician assistant										
Nurse practitioner				x						
Physicians (non-palliative)				x	x	x		x		
Intervention										
Patient interview										
Clinician interview			x		x	x	x	x		
Patient specific feedback										
Education session	x	x		x				x	x	
Follow up and consultation			x							x
Outcomes										
Confidence	↑	↑		↑				↑		
Frequency	↑			↑						
Knowledge	↑	↑		↑				↑		
Satisfaction with intervention	↑	↑						↑		
Satisfaction with care	↑									↑
Quality of communication	↑			↑					↑	
Quality of life									↑	↑
Descriptive Themes										
Lack of knowledge of the clinicians			x		x	x	x	x		
Author	Paladino	Coyle	Hielmfors	Lakin	Mitchell	Nedjat-	Raphael	Selman	Song	Zimmermann

						Hajem				
Year	2012	2015	2015	2017	2016	2017	2014	2016	2015	2014
Confusion in roles of various clinicians in end-of-life					x	x	x			
Patient and families concern about advance care planning					x					
Insufficient time							x			
End-of-life care is essential						x				