

**Improving End of Life Care: Symptom Assessment and Education for Informal Hospice
Caregivers (A Quality Improvement Project)**

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Abstract

Nature and scope of the project. In the setting of COVID-19, more individuals experience the dying process in their home rather than at hospice facilities. Currently, there are limited resources to help informal caregivers identify signs and symptoms of death and dying. The Edmonton Symptom Assessment System (ESAS) is a standardized assessment tool that can be offered in the hospice setting. This quality improvement (QI) project aims to increase utilization of the ESAS tool among caregivers with loved ones enrolled in hospice.

Synthesis and analysis of supporting literature. Without adequate education on how to care for dying patients, patients may experience decreased quality of life, and caregivers may experience role strain, anxiety, and fatigue. Utilization of the ESAS tool improves patient-reported quality of life at the end of life and decreases caregiver burden.

Project implementation: Eligible participants received a pre-survey inquiring about current knowledge and comfort level of performing assessments. Education on the ESAS tool was delivered to participants with a pamphlet including 21 ESAS questionnaires. Three weeks following education, a post-survey was offered to participants to assess changes in knowledge.

Evaluation criteria: Pre- and post-survey data was compared. Qualitative and quantitative data was collected to analyze the ease of use, comfort level, and understanding of the ESAS tool by caregivers after education.

Outcomes/Recommendations: There was one participant who reported improvement in comfort level and knowledge of end of life symptoms but experienced no change in response to end of life symptoms. Results of this QI project were limited by the lack of participant

involvement. Initial data suggests that caregivers find the ESAS tool user-friendly but is not beneficial for individuals with a prolonged hospice admission.

Improving End of Life Care: Symptom Assessment and Education for Hospice Patients and/or Caregivers (A Quality Improvement Project)

It is estimated that by the year 2060, one quarter of the United States population will be over the age of 65 (Mather et al., 2015). Individuals age in a variety of settings, such as at home providing self-care, assisted living centers, skilled nursing homes, memory care, or hospice centers. Caregivers for aging individuals often come in the form of family members or friends caring for their loved ones. These caregivers are referred to as informal caregivers, as they are not formally trained to provide healthcare services. To effectively care for those experiencing end of life, caregivers require educational resources to help assess and manage symptoms of their loved ones. Resources must be valid, accurate, user-friendly, and they must provide clinical significance to effectively be used by caregivers (Brooks et al., 2020).

Symptom management at the end of life is critical, considering that patients demonstrate both verbal and nonverbal signs and symptoms of discomfort, which require interventions. Often, informal caregivers do not have the tools to assess signs and symptoms at the end of life, making end of life care a challenge. This project proposal aims to outline a quality improvement (QI) project focused on improving standardized symptom assessments among patients and/or informal caregivers enrolled in hospice or palliative care programs.

The Problem Identification/Available Knowledge

In a study of 100 informal caregivers, 48.2% of participants reported insufficient knowledge regarding the purpose of hospice and how to take care of dying family members (Shalev et al., 2019). Without adequate education on how to care for dying patients, patients may experience decreased quality of life (QOL) and caregivers may experience role strain,

anxiety, grief, fatigue, and illness. Further, informal caregivers are more satisfied with their loved ones' end of life experience when communication and understanding are prioritized by the organization providing care, according to Hjörleifsdóttir et al. (2019). Many hospice organizations do not have tools in place to support caregivers with loved ones enrolled in hospice. However, the end of life process is extremely impactful on patients and family alike, which is why it is essential that caregivers are equipped with the resources to appropriately care for loved ones during death and the dying process.

The prevalence of informal caregivers providing end of life care has increased in the setting of COVID-19 for several reasons (Tyler et al., 2021). First, the number of staff providing in-home services was limited prior to COVID-19, but has significantly declined since the pandemic began. Reasons for the reduction in staff include limited personal protective equipment, lack of "essential worker" status, reduced benefits and pay, and limited training and career advancement opportunities.

Further, the lack of resources for informal caregivers has heightened within the context of COVID-19 due to restricted access for healthcare providers in the home and hospice staffing shortages, leading to an increased number of family members providing end of life care (Tyler et al., 2021). These factors have influenced the demand on informal caregivers to provide care to their loved ones at the end of life. In the context of COVID-19, patients do not always have a choice on where to receive end of life care if facilities are not taking new admissions. Sometimes home care is the only option for individuals, and care must be primarily delivered from loved ones.

There are direct and indirect costs to the hospice organization when informal caregivers are not properly trained on how to care for the patient. For patients, insufficient symptom management can lead to decreased QOL, which can pose both indirect and direct costs to facilities that provide care. In terms of care for informal caregivers, limited knowledge and understanding of symptoms can lead to increased phone calls to the hospice facility and unplanned emergency room visits (Hospice News, 2019). Additionally, limited education amplifies the demands of the hospice center to respond to individual questions, concerns, and grief, rather than having tools readily available for informal caregivers. It is essential that hospice staff have the educational tools available for patients and/or informal caregivers to access standardized symptom assessments at the end of life.

There is growing evidence that palliative care provides benefits to patient-centered care at the end of life (Brooks et al., 2020). Often, those experiencing end of life have a difficult time identifying and responding to symptoms to promote comfort (Buttenschoen et al., 2014). There are several tools that aid in the assessment of pain and discomfort, but often these tools are inaccessible to patients and/or informal caregivers due to time, financial limitations, or poor usability of a tool. Additionally, many tools require extensive education, which is a barrier to educating those experiencing end of life. The Edmonton Symptom Assessment System (ESAS) is a standardized assessment tool that subjectively and objectively identifies symptoms at the end of life. Providers can use this tool to monitor symptoms over time and appropriately guide goals of care conversations (Brooks et al., 2020).

Brooks et al. (2020) suggests that standardized symptom assessments, such as the ESAS tool, can help aid in patient and provider communication, facilitate visits, and support goals of

care. Not only do standardized assessments guide current care, but assessments also increase patient knowledge and understanding, self-management, and empowerment (Diplock et al., 2019). Ultimately, these components help improve patient satisfaction at the end of life. Implementation of the ESAS tool for informal caregivers offers the potential to increase QOL at the end of life and improve patient satisfaction.

PICOT Question

In the hospice setting, does increased utilization of the ESAS tool among patients and/or informal caregivers improve comfort level, knowledge, and increase interventions related to physical symptoms at the end of life?

Literature Review

It is essential for the researcher to be educated about the current literature related to the QI project. This information guides the development of the QI project and lends insight to the information already available on the topic. Current literature on the intervention, design, and results of studies involving the ESAS tool can be found in Appendix A.

Literature Synthesis

When conducting a literature review it is essential to complete a thorough review of appropriate databases to gather information. Not only is it essential to gather current research, practice guidelines, and recommendations for the use of an intervention, but it is also necessary to find background information about the problem. Background information, including significance, consequences, and theoretical frameworks, are a few of the foundational elements to a thorough literature review. To create an effective project proposal, a thorough and comprehensive literature review on the topic is required.

Literature Search Process

In this literature review, several databases were utilized to gather information. CINAHL Complete, MedLine Complete, Cochrane Library, and PubMed were the primary databases used. Search terms included: “hospice” OR “home health” OR “palliative” OR “end of life” OR “terminal illness” OR “dying” AND “caregiver” OR “family” OR “informal caregiver” OR “loved one” OR “proxy.” Results were further filtered to only include peer-reviewed articles from the year 2015 and beyond. Additional search terms were added to the search criteria, including “pain management” OR “pain scale” OR “discomfort”. At this point in the search, the problem was identified, and search terms specific to the ESAS were incorporated. These search terms included: “Edmonton Screening Assessment System” OR “ESAS” OR “screening tool”. The Cochrane Library had one result for this criteria, however MedLine Complete yielded about 300 results.

A qualitative study conducted by Chasen et al. (2015) identified the attitudes and actions of oncology providers towards the administration of the ESAS. Forty research participants took a four-item survey about the following topics: attitudes towards palliative care services, knowledge of local hospice resources, attitudes towards the ESAS, and knowledge of cancer care symptom management guidelines. Results determined that 74.4% of providers agreed that the ESAS enhances patient care and 84.6% of providers stated that the ESAS improves symptom assessment. However, due to the amount of time required to review the ESAS, only 20% of participants report always evaluating the results of the ESAS. A limitation of this study was that overall attitudes were related to general screening tools rather than the

ESAS specifically (Chasen et al., 2015). Positive provider feedback on the administration of the ESAS supports the implementation of the tool throughout various healthcare settings.

Lage et al. (2018) performed a prospective study on 932 individuals in the inpatient setting to determine how symptom severity would alter discharge plans. Patients who demonstrated higher ESAS scores were more likely to discharge to post-acute care (palliative care) or hospice, rather than returning home. However, it is also important to note that older age, living situation, impaired mobility, longer length of hospital stay, and higher depression and anxiety scores were also related to a likely discharge to palliative care or hospice. These findings present a significant limitation to the conclusions that can be drawn about the ESAS. However, it is important to acknowledge that the application of the ESAS can expedite the discharge process and allow patients and informal caregivers to optimize the end of life experience. Although there are several indications a patient may require palliative services, the ESAS is a tool that can be feasibly used by providers to aid discharge planning.

ESAS Interventions

Hui et al. (2016) conducted a systematic review to determine how the implementation of the ESAS in the outpatient setting impacts the number of outpatient palliative care consults. Literature was reviewed to determine current palliative referral criteria among different institutions. Of the 20 pieces of literature examined, six themes emerged as critical elements for the referral process. Referral criteria among studies included physical symptoms, cancer diagnosis, disease prognosis, performance status, psychosocial distress, and end of life planning. Of the 13 studies that focused on symptom management, only nine of the studies used a valid and reliable tool to assess symptoms of pain and seven of those nine used the

ESAS. Based on the use of the ESAS, among other tools, Hui et al. (2016) concluded that validated tools such as the ESAS increased the likelihood of outpatient palliative care referrals.

Tanco et al. (2018) administered the ESAS to both caregivers and patients to assess caregiver symptom burden. Results were compared to the Zarit Burden Interview-12, which is a validated tool to assess for caregiver burden. Though the ESAS is not meant to assess burden, aspects of the tool were compared to the Zarit Burden Interview-12 to understand potential overlap in results. Further, patient scores of the ESAS were compared to caregiver scores to understand any potential correlation between caregiver burden and higher symptom severity. Results demonstrated similarities between caregiver symptoms of fatigue and patient-reported fatigue. There was no statistically significant correlation between the burden reported on the ESAS and the burden of the Zarit Burden Interview-12 results. Generally, as patients reported increased burden of anxiety, fatigue, and financial distress, so did their respective caregivers. This information is critical for the provider to be aware of to provide holistic, patient-centered care.

Outcomes of ESAS Utilization

A mixed-methods study by Brooks et al. (2020) aimed to determine the way the ESAS improved communication between patients and providers' experiences at the end of life. Throughout 31 interviews, three themes emerged from respondents. Firstly, participants reported initial difficulty using the ESAS, specifically with rating particular symptoms. The difficulty came from conceptualizing the timeframe of ESAS utilization. Participants were asked to focus on symptoms over the past 24 hours, yet reported symptoms were often too variable to articulate within a 24-hour window. However, despite initial frustrations, respondents

claimed the ESAS was reported to improve awareness of symptoms. Recognition of symptom reporting was critical to understanding the relationship between an individual's mood and discomfort. Lastly, participants reported the ESAS helped facilitate communication with end of life providers. The ability to express feelings on a numeric scale offered greater understanding of baseline symptoms and day-to-day variation. Ultimately, Brooks et al. (2020) concluded that the ESAS increased patient and caregiver awareness of symptoms, daily symptom patterns, and communication.

Diplock et al. (2017) conducted a pre-post test to determine patient satisfaction before and after ESAS implementation. There were 109 participants who did not complete the ESAS and 108 participants who did complete the ESAS upon admission. Statistically significant improvements in health-related quality of life (HRQoL) were noted among the participants who completed the ESAS. Further, those who completed the ESAS reported increased satisfaction (PSC) compared to the group who did not perform the ESAS. Results were significant at a p-value of 0.05. Additionally, there was a positive correlation between decreased ESAS scores and symptom burden, however, these results were not statistically significant. Of note, there was no significant difference between each group regarding supportive care.

Organizational Project Information

The QI project was created to enhance standardized symptom assessments among informal caregivers providing care for loved ones enrolled in hospice. This project was implemented for a hospice organization that provides hospice care to patients that reside in a hospice house, or who receive home hospice services. This QI project was intended for caregivers who are the primary caretakers for their loved ones at the end of life. Patients

enrolled in home hospice programs, or a hospice house with primarily family caretakers were the main population served in this QI project. In the home setting, often an informal caregiver assists in caring for their loved one, in addition to a hospice nurse who periodically makes visits to the home. It is the role of the caregiver to assess the patient's symptoms and share information with hospice providers to help guide care. It is the role of the nurse to check in with the patient and caregiver and ensure proper resources are available.

Population

The participants in this QI project included both staff members at the hospice facility (including nurses, certified nursing assistants, social workers, and providers), as well as patients and their respective caregivers. The primary population served through this project were adults who qualified for hospice care and were cared for by an informal caregiver. The focus of the QI project was on newly admitted hospice patients, and patients who were currently enrolled and would benefit from standardized symptom education.

Inclusion and Exclusion Criteria

Inclusion criteria included adult patients over 18 years of age enrolled in a hospice center who are cared for by an informal caregiver. Exclusion criteria included patients under 18 years of age or physiologically unstable patients with an anticipated death within two weeks.

Interprofessional Team

The interprofessional team was critical at each phase of the QI project. The interprofessional team included hospice providers, the director of Quality and Compliance, and the doctor of nursing practice (DNP) student. Interprofessional team members were identified early in the QI project proposal and were fundamental to the creation, implementation, and

evaluation of the QI project. The interprofessional team had insights about the organization that the DNP student did not such as specific role responsibilities, and communication strategies.

Stakeholders

Hospice staff members were key stakeholders in this QI project. Other stakeholders included hospice providers, the executive director of the hospice organization, informal caregivers, and patients who participated in the project. Stakeholder support was essential to gain support and interest prior to the implementation of the QI project. Stakeholders were involved in each meeting with the DNP student to ensure clarity and transparency in the decision-making process.

The Gap Analysis

Often, the caregivers of individuals enrolled in hospice do not have the knowledge or skills necessary to adequately assess verbal and nonverbal signs of pain. According to a nurse practitioner at a hospice facility “family caregivers often delay treating pain and discomfort unless the patient can explicitly state they are having pain. But hospice patients usually demonstrate nonverbal signs of pain such as restlessness and agitation, and these signs are left untreated” (personal communication, February 22, 2021). Further, the nurse practitioner explains “opioid medications are a cornerstone of treating pain among hospice patients, however there is a stigma associated with opioid medications for family members, which results in lack of intervention to signs and symptoms of pain.” Many tools currently available are based on subjective assessments, meaning the individual making assessments is relying on the patient’s verbal expression of symptoms rather than the patient’s verbal and nonverbal

cues. Fromage and Hatti (2015) comment that patients who are unable to verbally communicate their needs often have untreated pain and discomfort. Additionally, the concept of pain has cultural implications, further demonstrating the importance of an objective pain assessment tool.

Proposed Solution

The ESAS tool was developed in 1991 to assess symptoms of pain and distress among cancer patients (Hui & Bruera, 2017). Originally, the ESAS tool was developed in Ontario, Canada, in the setting of end-stage cancer patients on an inpatient palliative care unit (Brooks et al., 2020). However, the ESAS tool has since been utilized in cardiology, nephrology, hepatology, intensive care units, and long-term care facilities (Buttenschoen et al., 2014). Since the development of the tool, the ESAS has been translated into over 20 languages with proven validity and reliability throughout time, culture, and language.

The original ESAS tool assessed fatigue, pain, anorexia, cachexia, dyspnea, anxiety, and depression. Over time, however, the ESAS tool has evolved with the Visual, Analog, Scale (VAS) to create the ESAS-Revised (ESAS-r) (Brooks et al., 2020). The ESAS-r assesses pain, nausea, activity, depression, anxiety, drowsiness, appetite, and sensation of well-being. The merging of these two tools allows the provider to group symptoms together and develop a comprehensive understanding of the patient's status (Hui & Bruera, 2017). The ESAS originally took note of the symptoms at the current moment, whereas the VAS assessed for symptoms over time. As the two tools merged and created the ESAS-r, the tool now offers a 24-hour snapshot of the patient's condition. The remainder of this paper will not differentiate between the ESAS and the ESAS-r, as the use of each tool is based on facility preference.

The QI project was created to increase utilization of the ESAS tool among patients and/or informal caregivers. Increased ESAS utilization has the ability to increase patient QOL and patient satisfaction, and decrease caregiver burden (Tagami et al., 2020; Tanco et al., 2018). In this project, the DNP student created educational content for patients and/or informal caregivers to learn about the ESAS tool and guide symptom assessment and management.

Needs Assessment

Hospice organizations serve communities through a 24-hour hospice house, home hospice services, and hospice services at nursing homes/assisted living centers. Aside from hospice services, many organizations also offer grief support to family members after the death of a loved one. While grief support is a helpful tool after death, there is a lack of resources available for caregivers leading up to death, and during the dying process. Currently, there are no standardized or validated tools available for informal caregivers to utilize at the end of life. The QI project attempted to increase the availability of resources among caregivers.

Strengths, Weaknesses, Opportunities and Threats Analysis

Teamwork and collaboration were strengths of many hospice organizations. Staff members were frequently in coordination with providers, and providers were in constant communication with agency leadership. A weakness of hospice organizations included the lack of centralized education for caregivers. Many facilities serve patients at many different locations, so the lack of centralized education was often heightened in the context of many areas of hospice care. Further, staff were often not provided the same resources, making centralized education difficult to achieve. Opportunities for many hospice organizations included the expansion of educational resources for patients and informal caregivers through

technology platforms such as videos, social media platforms, and phone app development.

There were no immediate threats to hospice organizations; however, in each community there were many competing hospice agencies that could divert patients away from other hospice centers, creating a potential threat.

Guiding Theoretical Framework and Change Theory

To appreciate the breadth and depth of the ESAS, it was essential to first understand the Humanistic Nursing Theory (HNT). In the original study of the HNT, Paterson and Zderad (1976) eloquently define the theory as a “phenomenon of nursing as it is experienced in the everyday world” (p. 23). Nurse-patient relationships are fundamental to the HNT. Specifically, the value of interactions between the nurse and patient to achieve well-being (Wu & Volker, 2012). In the setting of hospice care, the nurse role is often fulfilled by the informal caregiver.

The HNT identifies the importance of human individuality at the end of life experience. Each individual experiencing end of life will have a different experience based on their past experiences and perspectives, and it is the role of the nurse to appreciate differing values. The HNT focuses on the unique patient experience and the role of the nurse helping the patient manage end of life. The ESAS is designed not only to understand symptoms of pain and discomfort, but it also helps the nurse and informal caregiver treat the patient’s individual needs. Administration of the ESAS is critical to understand the patient’s experience of pain and perform necessary interventions to alleviate the patient’s feelings of discomfort.

Change Theory

The conceptual framework to utilize the ESAS is best understood through the Plan, Do, Study, Act (PDSA) model. The PDSA model is a cyclical process of implementation and reflection

(Sollecito & Johnson, 2020). Throughout each phase of project implementation, researchers respond to each phase of the cycle to adjust the project and improve outcomes. In a 2020 study by Nakazawa et al., (2020), researchers prepared a QI project to increase the number of palliative care consults based on identifying factors. The PDSA was utilized to encourage providers to self-check their consultation rates in the hospital. Results of the study demonstrated that 90% of providers using the PDSA plan reported satisfaction with the PDSA regarding their own palliative care consult rate. Nakazawa et al., (2020) demonstrated the benefits of a cyclical PDSA to offer end of life resources.

Aims/Goals/Objectives Clarified

The mission statement of this QI project is *to promote QOL among those experiencing the death and dying process*. Many hospice organizations focus their mission statements on providing patient centered, individualized, compassionate, and supportive care to those experiencing the death, dying, or loss process. This QI project incorporated major themes from several hospice organizations in the creation of a mission statement. The core elements of compassionate care, education, and support for the dying were weaved through both the mission statement of this project as well as many other hospice organizations.

The primary goal of the QI project was to increase utilization of the ESAS tool. With increased utilization of the ESAS tool, it is the hope that caregivers would experience greater knowledge, and comfort assessing signs and symptoms at the end of life, and improved response to physical assessments. As mentioned in previous sections of this paper, the use of the ESAS tool lends staff, patients, and/or informal caregivers the opportunity to better

understand and serve individuals at the end of life. Education about the ESAS tool for patients and/or informal caregivers will be the primary way to increase utilization of the tool.

SMART Objectives

The mission statement and project goal as noted above was supported by six essential program objectives described below. A detailed description of implementation strategies and evaluation techniques for each objective are described below. These objectives will ultimately help reach the goal to increase comfort, knowledge, and utilization of the ESAS tool.

Objective One

The first objective was to create pre- and post-surveys for patients and/or informal caregivers to complete prior to the project's Institutional Review Board (IRB) approval. This objective required the DNP student to create pre-and post-intervention surveys with the guidance of primary stakeholders. Issel (2018) identified the importance of a pretest to gather baseline information and have data available to compare results at the end of an intervention.

Implementation. In the development of objective one, the pre-and post-surveys were made to assess the caregiver's level of comfort assessing pain, responding to pain, and familiarity with tools to understand pain. The following questions were asked and graded on a five-point Likert scale: On a scale of one to five, how comfortable do you feel assessing end of life symptoms in yourself/your loved one; on a scale of one to five, how comfortable do you feel responding to end of life symptoms in yourself/your loved one; and on a scale of one to five, how familiar would you say you are with understanding signs and symptoms of pain within yourself/your loved one? The Likert scale considered a score of one (1) as not at all and five (5) as extremely. The pre-survey inquired about standardized tools that were already being utilized

by caregivers and/or patients, however, this question was not addressed in the post-survey. See Appendix D for further information on the pre-intervention survey.

Both the pre- and post-intervention surveys had similar questions with the addition of three questions on the post-survey. The post-survey asked three additional questions: In the past week, how many days did you use the ESAS tool to assess for pain and discomfort; in the past week, how many days did you intervene to treat pain and discomfort based on the ESAS score; and in the past week, how many days did you choose not to use the ESAS due to time constraints? Each question had answer choices based on a Likert scale: never, one to two days, two to four days, five to six days, or every day. See Appendix E for documentation of the post-survey.

Language barriers were a limitation to the development of both the pre- and post-surveys. The pre- and post-surveys were only created in the English language, and thus were not accessible to patients whose primary language was not English. The language barrier poses additional costs to hospice organizations, such as purchasing a translator service to complete the survey. Again, stakeholders were involved in the development of the post-survey. Both surveys were developed prior to IRB approval.

Outcome Measures. To evaluate if this outcome was met, the objective had a met or not met measurement.

Objective Two

The second objective of this QI project was to disseminate the pre-survey to patients and/or informal caregivers within the first month of the project implementation.

Implementation. The key stakeholders and interprofessional team determined that the admissions team, along with the nursing staff, would be most suited to help disseminate the pre-survey. The thought was that at the time of admission, the admissions team could communicate with families about the QI project taking place at the organization. Further, they could educate interested individuals about an in-person meeting with the DNP student, to determine whether they would be interested in participation. Hard copies of the pre-survey were available at the hospice facility for admissions staff to utilize.

Outcome Measures. This objective was measured by the number of pre-surveys disseminated by the end of the first month. The goal was to have 25 surveys completed and returned to the student by the end of the first month, however, the timeline was subject to change based on patient census at the time of implementation.

Objective Three

Objective three was for the DNP student to create an educational pamphlet to educate caregivers on the ESAS tool prior to IRB approval. According to González-Fraile et al. (2021), educational resources for caregivers are necessary for providers to offer quality care. Research by González-Fraile et al. (2021) suggested that providing interventions to caregivers that promote training and education may reduce both caregiver burden and depressive symptoms. Increasing the availability of education offered by the hospice organization could help caregivers provide better care while simultaneously reducing the risk of caregiver burden. This objective supported the goal to increase patient and/or informal caregiver utilization of the ESAS tool.

Implementation. A paper document was created by the DNP student for patients and/or informal caregivers, with the assistance and approval of the hospice facility stakeholders. The document included information about the purpose of the ESAS tool, how to interpret results, when to use the tool, and who can use the tool. The pamphlet also included a page describing common signs and symptoms of each element of the ESAS tool. This page gave examples of both verbal and nonverbal common signs and symptoms. The remainder of the pamphlet included blank ESAS scales for participants to complete. See Appendix F for further details.

Outcome Measures. To evaluate if this outcome was met, the objective had a met or not met measurement.

Objective Four

The fourth objective was for the DNP student to disseminate ESAS education to patients and/or informal caregivers during the first month of the project.

Implementation. The DNP student created 25 paper copies of the educational pamphlet. The pamphlet was to be delivered to informal caregivers and/or patients at the same time the pre-survey was administered. Education could take place in person or virtually via Zoom to comply with COVID-19 precautions. Education was created with the help of stakeholders at the hospice organization. See Appendix F for informal caregiver ESAS education.

Outcome Measure. There were limitations to education dissemination, such as language and cultural barriers. The education was only created in the English language, as this was the population predominantly served through the QI project. Education took about ten

minutes to complete. The outcome of this objective was measured nominally, and the objective was met.

Objective Five

The fifth objective was to disseminate the post-survey to patients and/or informal caregivers and patients three weeks following the pre-survey and ESAS education.

Implementation. The DNP student provided the hospice organization with 25 printed copies of the post-survey for informal caregivers. The post-survey was only available to patients and/or informal caregivers who completed the pre-survey and participated in ESAS education. It was possible to complete the post-survey in person, virtually via Zoom, or virtually via a QR code. The purpose of the QR code was to help avoid unnecessary COVID-19 exposures. The post-surveys collected via the QR code did not require patient identifiers. The post-survey can be found in Appendix E. The QR code can be found in Appendix F. Hard copy documentation of the surveys were stored at the hospice organization to maintain patient confidentiality. The DNP student worked with stakeholders at the hospice facility to record who completed the education and pre-survey in patient charts. The DNP student monitored which caregivers completed the education and pre-survey and added a reminder for the post-survey in the patient's chart.

Outcome Measures. This objective was evaluated by the number of post-surveys completed three weeks following ESAS education, with a goal of 25 surveys completed.

Objective Six

Objective six was for the DNP student to collect data from the pre- and post-surveys and analyze the results to determine which project goals were met in the third month of the project.

Implementation. In this objective, the DNP student collected completed surveys from patients and/or informal caregivers to analyze data from the pre- and post-surveys. The DNP student compiled the data and made comparisons between pre- and post-survey answers. Stakeholders were involved in the process to provide the DNP student facility access to analyze surveys that were stored at the hospice organization. The DNP student analyzed statistical and descriptive data to draw conclusions.

Outcome Measures. The goal of objective six was to observe improvement in comfort level assessing signs and symptoms at the end of life, increased knowledge in end of life assessments, and improved interventions to signs and symptoms. To get this number, the project lead compared participant responses from the pre-survey to participant responses in the post-survey. From here, the DNP student used Intellectus Statistics to enter data and develop statistical analyses of differences in perceived pain assessments before and after ESAS education.

Gantt Chart

A timeline was created for the QI project to ensure that goals were being met during a realistic timeframe. This QI project was intended to take place over a three-month period. Prior to beginning the project, creation of the pre- and post-intervention surveys and educational pamphlet was required, due to IRB approval. Once the DNP student received IRB approval,

project implementation began. Table 1 identifies the goals at the timeline in which they will be achieved. For further clarification on each objective's timeline refer to Appendix B.

Logic Model

See Appendix C for a logic model related to implementation of this QI project.

Budget

The costs of this project were limited to the printing required to print pre-survey, ESAS pamphlets, and post-survey documentation. There were no additional costs for the QR code, project, facilities, or communication tools. There were potential costs associated with the translation of education materials to other languages, however, in this QI project, no other languages were utilized in resources.

Methodology and Analysis

To ensure that the QI project could be replicated in other settings, it was important to specify the methods used in each phase of the project. Pre-implementation, implementation, and post-implementation methods were discussed for QI project clarity and understanding. During the pre-implementation phase, the pre- and post-survey, and ESAS education material was created with the stakeholders at the organization. Both surveys were completed and approved by the IRB prior to implementation of the project. Objectives one and three were met in the pre-implementation phase.

Hospice staff were informed of the project goals, purpose, and objectives after IRB approval, and prior to project implementation. This took place on virtual Zoom meetings with the DNP student, stakeholders, hospice admissions staff, and the social work team. Staff involvement was critical to the onboarding process of the project to promote and sustain

change. There were four Zoom meetings that took place before the project workflow was solidified.

Intervention Plans

Prior to implementation of the project, there were several discussions on the best way to build participation in the study. Initially, the admissions team was targeted as the primary team of project recruiters, considering they often have interactions with patients and informal caregivers early on. However, upon further discussion, the admissions team felt as though offering participation in a project would be overwhelming at the first meeting. Further, because currently admitted patients were eligible for participation it was ultimately decided the admissions team would not communicate project goals.

From here, discussions were had about the nursing staff leading conversations with patients and caregivers, but at the time, there was a robust surge of COVID-19 taking place and nursing staff felt as though the addition of a QI project would be a difficult commitment. Ultimately, it was determined that the social work team would primarily lead conversations with patients and/or informal caregivers about participation in this QI project. There was a group of social workers who provided services to patients and families primarily at the organization's hospice house and another group of social workers who provided home hospice services. At the time, it was decided that participants could be best identified between the two groups of social work teams.

The project was first implemented with the social work team communicating with potential participants. The DNP student offered a standardized script for the social work team to utilize when talking to families to ensure the message delivered was the same for all

patients. The purpose of the standardized script was to ensure interested participants received the same information at the initiation of the QI project to manage or mitigate the risk of message variation. The following outline was offered:

I want to let you know about a project that is taking place at the hospice center that you may be interested in. The hospice facility is working with a nurse practitioner student on education for family members caring for their loved ones in hospice. The goal of this education is to help family members easily identify signs and symptoms of pain and discomfort among their loved ones. We know that you (family members/friends) spend the most time with your loved one and we feel it is important to give you the tools to help both your loved one and yourself. The time commitment for education includes one in-person meeting with the student that will take between 10 minutes and 20 minutes. If you're interested in learning more about this project, please let me know and the student will reach out to share more about the project and find a time to meet with you.

Once the social work team determined participants that may be interested in the QI project, the social worker messaged the DNP student on a secure platform. The secure platform that was utilized for communication was the Qliq application. Qliq is an application used by the hospice facility staff to communicate secure messages with other staff. The team of social workers determined that communication via the Qliq application would be the most secure, reliable, and convenient. The social work team utilized knowledge about the QI projects inclusion and exclusion criteria to determine eligible participants in the study. The DNP student

kept track of participants using the Qliq application, rather than via paper copies stored at the hospice facility.

The post-implementation phase of this QI project involved gathering and analyzing completed pre- and post-surveys. There was only one participant in the project so statistical measures were unable to be performed. Survey responses were analyzed at two different points in time (before and after ESAS education), but no statistical measures were completed. With more participants, a paired t-test would have been an effective way to analyze data and determine statistical significance. The independent variable would be participants completing each survey and the dependent variables would be the following categories: assessment of pain, response to pain, and comfort level intervening to positive pain ratings. The paired t-test could compare responses among the same group at two different points in time and offer insight to the change in attitude and assessment before and after the implementation of the ESAS tool. However, with limited participation, there were no statistical analyses performed.

IRB/Ethical Considerations

Development of a QI project must consider IRB guidelines. This QI project obtained approval from the college's IRB. In this project, there were no vulnerable subjects used. The primary subjects were informal caregivers and/or patients currently enrolled in hospice. Participants were educated that program participation was completely voluntary and withdrawal of participation would not affect the care provided by the hospice organization. Further, there would be no consequences to withdrawal of participation during the course of the project. There was no identifying information utilized in this project. The pre-survey, ESAS education, and post-survey did not include any identifying patient information. At the

completion of the project, the ESAS pamphlet remained in the possession of the informal caregiver and was not collected in the QI project. Risks and discomforts were minor, mostly including time commitments, but were outlined to the IRB and participants alike.

If the caregiver was not interested in completing the ESAS pre- or post-surveys or the education itself, the project lead must respect the wishes of the patient as outlined in the American Nurses Association (ANA) Code of Ethics (2015), provision 1.2. Under Provision 3 of the Code of Ethics the nurse must promote confidentiality and privacy of information.

Implementation

The implementation phase of the project took place when the social work team contacted eligible participants and communicated findings with the DNP student. The goal was to gather participants in the first month of project implementation. There was one social work team member who kept the project lead up to date on the status of eligible participants. After two weeks of project implementation, the social worker reached out with information on several eligible participants who did not participate for various reasons. The first several participants who were eligible chose not to participate for the following reasons: concerns about hospice in general and the social worker did not feel it was appropriate to introduce a project, a family member concerned that the last memories with their loved one would be a clinical project, and, finally, one caregiver worked with taxes and felt there was too much to do with tax season approaching.

The DNP student was contacted by the social work team with the name and phone number of one interested participant in the third week of implementation. Following communication with the social work team, the DNP student reached out to the participant via

phone call and shared more information about the DNP project, the ESAS tool, and the requirements from the participant. At this point, the participant expressed interest in project participation, as they felt they may benefit from this opportunity. The DNP student coordinated a time to meet with the participant in person. The meeting was 20 minutes long, and the patient enrolled in hospice was present for the duration of the meeting. The pre-survey was given to the participant first, followed by ESAS education. The ESAS education pamphlet was left with the participant at the conclusion of the meeting.

With the lack of participant interest expressed from one social worker and the limited feedback from the remainder of the social work team, the project leaders determined that having the pre-survey and education readily available at the hospice house and hospice organization would be the best way to gather participants. The project lead gave ten copies to both the hospice house and the hospice organization for distribution as necessary. According to hospice staff, two pre-surveys were delivered at the hospice house, but they were not completed. Implementation of this project was two months total.

Results from Data Collection

There was one participant who enrolled in the QI project. Due to the limited participation, Intellectus Statistics were not utilized to analyze data. Refer to Table 2 for results on the pre-survey. When inquiring about current resources utilized to determine end of life symptoms in their loved one, the informal caregiver reported that they did not use formal resources, but relied on past experience and knowledge as a nurse. For this project, that is considered a “no” on question four of the pre-survey.

The post-survey, which identifies changes made over time, was administered in a follow-up phone call with the informal caregiver. The phone call was conducted at the three week increment with no reply, and again at 25 days. The post-survey was administered at the 25 day follow up. Refer to Table 2 for results of the post-survey. The informal caregiver reported using the ESAS tool between five and six days per week for the last three weeks but reported only responding to symptoms between one and two days per week. The informal caregiver in this project reported that days when they did not use the ESAS was related to forgetfulness, more so than time restraints.

Discussion of Data

From the pre-survey to the post-survey, the informal caregiver reported improved comfort assessing end of life symptoms and understanding signs and symptoms of death but remained consistent in their response to end of life signs. In conversation with the informal caregiver, it was reported that the patient consistently had a depression score of four to six on the ESAS tool. The informal caregiver expressed this scoring with the hospice nurse at a home visit and the hospice nurse inquired whether changes needed to be made to the treatment plan. The participant reported feeling that the ESAS brought awareness to the patient's level of depression for the first time.

When discussing the post-survey with the informal caregiver, the informal caregiver reported that the patient transitioned to hospice after experiencing a significant heart failure exacerbation in addition to dementia. The informal caregiver reported that the ESAS tool was not particularly specific to the dementia symptoms that the patient was experiencing. The informal caregiver commented that a resource pertaining to dementia specifically would be

helpful in their case. Lastly, the informal caregiver reported that because the patient did not have an impending death, they did not feel the ESAS questionnaire was helpful to guide the day-to-day care. The qualitative feedback given by the informal caregiver gave great insight to the utilization of the ESAS tool, in ways which the pre- and post-surveys could not assess.

During the pre-implementation phase, stakeholders reported that individuals who were “transitioning” to death, were identified as having two weeks or less of life. These individuals were not considered for the QI project, as the addition of a project could be burdensome. However, feedback from the participant in this study suggests that the tool may be more helpful when there is an impending death as the items being measured are specific to end of life.

Limitations

Limitations to this study include the lack of participation in the program. With only one participant, statistical measures were unable to be performed. The one participant in this project had previous nursing experience. It is difficult to know how an individual without any prior medical knowledge would respond to using the ESAS tool. Unfortunately, with limited participants, there was limited data as to how the tool was received by individuals without medical expertise.

Dissemination

There was limited evidence to support the widespread dissemination of ESAS use for informal caregivers and/or patients enrolled in hospice. Data from one participant suggests that the tool was not helpful for individuals who will be in hospice for an anticipated long period of time. If this QI project were to be disseminated, it would be helpful for the educator to clarify

that the ESAS measures for common signs and symptoms at the end of life. It does not consider individual illness, but rather a cluster of symptoms common to most individuals during the death and dying process.

Conclusion

It is critical that organizations offer resources for informal caregivers to appropriately assess and manage symptoms at the end of life. Witnessing a loved one enduring pain and discomfort at the end of life can be an uncomfortable and painful experience to observe. Evidence suggests that with improved assessment tools at the end of life, caregivers report decreased burden and patients experience improved QOL at the end of life. It is the responsibility of hospice organizations to provide adequate resources to caregivers who provide end of life care. In the setting of COVID-19, more tools and resources must be allocated for informal caregivers due to the shortage of hospice staff, limited resources, and risk of disease exposure.

Education and resources can help empower informal caregivers to participate in their loved ones' care and ultimately improve the patients QOL at the end of life. There are several resources available, but this QI project focused on the ESAS tool. The ESAS tool is a standardized assessment tool that measures subjective and objective signs and symptoms at the end of life. It is a tool that is currently used by many hospice and palliative organizations, and it takes limited time to educate individuals on the use of the ESAS tool. While it is difficult to make recommendations for future use of the ESAS tool among informal caregivers based on this QI project alone, it is important that hospice organizations continue to find resources to help families and friends care for their loved ones at the end of life.

References

- American Nurses Association. (2015, January). *Code of Ethics for Nurses*. American Nurses Association. <https://www.nursingworld.org/coe-view-only>
- Brooks, J. V., Poague, C., Formagini, T., Sinclair, C. T., & Nelson-Brantley, H. V. (2020). The role of a symptom assessment tool in shaping patient-physician communication in palliative care. *Journal of pain and symptom management*, *59*(1), 30–38. <https://doi.org/10.1016/j.jpainsymman.2019.08.024>
- Buttenschoen, D., Stephan, J., Watanabe, S., & Nekolaichuk, C. (2014). Health care providers' use and knowledge of the Edmonton Symptom Assessment System (ESAS): is there a need to improve information and training? *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *22*(1), 201–208. <https://doi-org.akin.css.edu/10.1007/s00520-013-1955-8>
- Chasen, M., Bhargava, R., Dalzell, C., & Pereira, J. L. (2015). Attitudes of oncologists towards palliative care and the Edmonton Symptom Assessment System (ESAS) at an Ontario cancer center in Canada. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *23*(3), 769–778. <https://doi-org.akin.css.edu/10.1007/s00520-014-2411-0>
- Diplock, B. D., McGarragle, K. M. C., Mueller, W. A., Haddad, S., Ehrlich, R., Yoon, D.-H. A., Cao, X., Al-Allaq, Y., Karanicolas, P., Fitch, M. I., Myers, J., Mitchell, A. J., & Ellis, J. W. M. (2019). The impact of automated screening with Edmonton Symptom Assessment System (ESAS) on health-related quality of life, supportive care needs, and patient satisfaction with care in 268 ambulatory cancer patients. *Supportive Care in Cancer :*

Official Journal of the Multinational Association of Supportive Care in Cancer, 27(1), 209–218. <https://doi-org.akin.css.edu/10.1007/s00520-018-4304-0>

Fromage, B., & Hatti, M. (2015). The pain experience according to a phenomenological view on palliative care. *L'Encephale*, 41(6), 462–469.

<https://doi-org.akin.css.edu/10.1016/j.encep.2014.10.019>

González-Fraile, E., Ballesteros, J., Rueda, J.-R., Santos-Zorrozuía, B., Solà, I., & McCleery, J. (2021). Remotely delivered information, training and support for informal caregivers of people with dementia. *The Cochrane Database of Systematic Reviews*, 1, CD006440.

<https://doi-org.akin.css.edu/10.1002/14651858.CD006440.pub3>

Hjörleifsdóttir, E., Einarsdóttir, A., Óskarsson, G. K., & Frímannsson, G. H. (2019). Family Caregivers' Satisfaction With Specialized End-of-Life Care Provided at Home: Assessment of the Psychometric Characteristics of the Icelandic Version of the Family Assessment of Treatment at the End of Life Questionnaire. *Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association*, 21(5), 412–421. <https://doi-org.akin.css.edu/10.1097/NJH.0000000000000583>

Hospice News. (2019, June 10). *Family caregiver training helps keep hospice patients at home.*

<https://hospicenews.com/2019/06/10/family-caregiver-training-helps-keep-hospice-patients-at-home/>

Hui, D., & Bruera, E. (2017). The Edmonton Symptom Assessment System 25 years later: Past, present, and future developments. *Journal of pain and symptom management*, 53(3), 630–643. <https://doi.org/10.1016/j.jpainsymman.2016.10.370>

- Hui, D., Meng, Y. C., Bruera, S., Geng, Y., Hutchins, R., Mori, M., Strasser, F., & Bruera, E. (2016). Referral criteria for outpatient palliative cancer care: A systematic review. *The oncologist*, 21(7), 895–901. <https://doi.org/10.1634/theoncologist.2016-0006>
- Issel, L. M. (2018). *Health program planning and evaluation: A practical, systematic approach for community health* (4th ed.). Sudbury, MA: Jones and Bartlett Publishers. ISBN: 9781284112115.
- Lage, D. E., Nipp, R. D., D'Arpino, S. M., Moran, S. M., Johnson, P. C., Wong, R. L., Pirl, W. F., Hochberg, E. P., Traeger, L. N., Jackson, V. A., Cashavelly, B. J., Martinson, H. S., Greer, J. A., Ryan, D. P., Temel, J. S., & El-Jawahri, A. (2018). Predictors of posthospital transitions of care in patients with advanced cancer. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 36(1), 76–82. <https://doi-org.akin.css.edu/10.1200/JCO.2017.74.0340>
- Mather, M., Jacobsen, L.A., & Pollard, K.M. (2015). Aging in the United States. Population Reference Bureau Population Bulletin. Retrieved from <https://www.prb.org/wp-content/uploads/2016/01/aging-us-population-bulletin-1.pdf>
- Nakazawa, Y., Sakashita, A., Kaizu, M., Abo, H., Ise, Y., Shinada, Y., Sugano, K., Yamashiro, A., Akizuki, N., & Kato, M. (2020). A self-check program targeting quality improvement in a hospital-based palliative care consultation team, Japanese society for palliative medicine: Issues regarding team activities identified through the plan-do-check-Act cycle. *Journal of Palliative Medicine*, 23(3), 359–367. <https://doi-org.akin.css.edu/10.1089/jpm.2019.0236>
- Paterson, J., & Zderad, L. (1976). *Humanistic Nursing*. Wiley.

- Shalev, A., Phongtankuel, V., Reid, M. C., Czaja, S. J., Dignam, R., Baughn, R., Newmark, M., Prigerson, H. G., Teresi, J., & Adelman, R. D. (2019). Home hospice caregivers' perceived information needs. *The American Journal of Hospice & Palliative Care*, *36*(4), 302–307. <https://doi-org.akin.css.edu/10.1177/1049909118805413>
- Sollecito, W. A., & Johnson, J. K. (2020). *McLaughlin and Kaluzny's continuous quality improvement in health care* (5th ed.). Jones & Bartlett Learning.
- Tagami, K., Kawaguchi, T., Miura, T., Yamaguchi, T., Matsumoto, Y., Watanabe, Y. S., Uehara, Y., Okizaki, A., Inoue, A., Morita, T., & Kinoshita, H. (2020). The association between health-related quality of life and achievement of personalized symptom goal. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *28*(10), 4737–4743. <https://doi-org.akin.css.edu/10.1007/s00520-020-05316-0>
- Tanco, K., Vidal, M., Arthur, J., Delgado Guay, M., Hui, D., Liu, D., Chisholm, G., & Bruera, E. (2018). Testing the feasibility of using the Edmonton Symptom Assessment System (ESAS) to assess caregiver symptom burden. *Palliative & Supportive Care*, *16*(1), 14–22. <https://doi-org.akin.css.edu/10.1017/S1478951517000098>
- Tyler, D., Hunter, M., Mulmule, N., & Porter, K. (2021). Covid-19 Intensifies Home Care Workforce Challenges. U.S. Department of Health and Human Services. <https://aspe.hhs.gov/reports/covid-19-intensifies-home-care-workforce-challenges>
- Wu, H.-L., & Volker, D. L. (2012). Humanistic Nursing Theory: application to hospice and palliative care. *Journal of Advanced Nursing*, *68*(2), 471–479. <https://doi-org.akin.css.edu/10.1111/j.1365-2648.2011.05770.x>

Table 1*Timeline of Project Objectives*

	Pre IRB-Approval	Month 1	Month 2	Month 3
Objective One	X			
Objective Two		X		
Objective Three	X			
Objective Four		X		
Objective Five			X	
Objective Six				X

Table 2*Pre- and Post-Survey Results*

Item Measured	Pre-Survey (Time 1)	Post-Survey (Time 2)
1. On a scale of 1-5 how comfortable do you feel assessing end of life symptoms in yourself/your loved one?	4 = Mostly	5 = Extremely
2. On a scale of 1-5 how comfortable do you feel responding to end of life symptoms in yourself/your loved one?	4 = Mostly	4 = Mostly
3. On a scale of 1-5 how familiar would you say you are with understanding end of life symptoms within yourself/your loved one?	4 = Mostly	5 = Extremely
4. In the past week, how many days did you use the ESAS tool to assess signs and symptoms of your loved one?	N/A	5-6 Days
5. In the past week, how many days did you intervene to treat end of life symptoms based on the ESAS score of yourself/your loved one?	N/A	1-2 Days
6. In the past week, how many days did you choose not to use the ESAS tool due to time restraints?	N/A	Never

Appendix A

Reference	Purpose/Question	Design	Sample	Intervention	Results	Notes
Chasen, M., Bhargava, R., Dalzell, C., & Pereira, J. L. (2015). Attitudes of oncologists towards palliative care and the Edmonton Symptom Assessment System (ESAS) at an Ontario cancer center in Canada. <i>Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer</i> , 23(3), 769–778. https://doi-org.akin.css.edu/	To assess attitudes of the ESAS tool among medical oncologists (MO), radiation oncologists (RO), and general practitioners (GP).	Qualitative	40 participants	The survey was assessed for four different items. 1. Oncologists attitudes towards palliative and palliative care services. 2. Knowledge of local hospice palliative care resources 3. Attitudes to standardized symptom assessment and the ESAS 4. Knowledge of Cancer Care Ontario's Symptom Management Guidelines. Participants were assessed on a four-point Likert scale including "completely disagree", "disagree", "agree", and "completely agree".	Section three of the survey was the primary focus for this paper. MO's, RO's, and GP's all agreed that the ESAS effectively assessed for severity of symptoms and improved patient care. However, there is a gap in practice between the attitudes providers feel about the ESAS and overall administration of the assessment tool.	This study took place in Ontario, Canada.

<u>10.1007/s00520-014-2411-0</u>						
<p>Kako, J., Kobayashi, M., Kanno, Y., Ogawa, A., Miura, T., & Matsumoto, Y. (2018). The optimal cutoff point for expressing revised Edmonton Symptom Assessment System scores as binary data indicating the presence or absence of symptoms. <i>The American Journal of Hospice & Palliative Care</i>, 35(11), 1390–1393. https://doi.org.akin.css.edu/10.1177/1049909118775660</p>	<p>To understand how the Revised ESAS-r tool is used to rate the severity of symptoms among those with terminal illness. Sensitivity and specificity of the ESAS-r are compared to the ESAS.</p>	<p>Retrospective design</p>	<p>157 patients completed the ESAS-r</p>	<p>Patients ranked the following symptoms on a 1-6 scale: dyspnea, nausea, tiredness, pain, lack of appetite, and drowsiness.</p>	<p>Dyspnea, nausea, tiredness, pain, and lack of appetite all showed specific and sensitive results compared to the original ESAS. Drowsiness on the other hand was not sensitive or specific to symptoms compared to the original ESAS and needs further assessment. At a p-value of 0.05, drowsiness demonstrated 0.55 specificity. The threshold for results was 0.7.</p>	<p>Intervention. Published by the American Journal of Hospice and Palliative Care.</p>

<p>Hui, D., & Bruera, E. (2017). The Edmonton Symptom Assessment System 25 years later: Past, present, and future developments. <i>Journal of pain and symptom management</i>, 53(3), 630–643. https://doi.org/10.1016/j.jpainsymman.2016.10.370</p>	<p>To determine the necessity of routine ESAS assessments and describe the progression of how the ESAS was developed.</p>	<p>Narrative Review</p>	<p>N/A</p>	<p>The ESAS was developed in 1991 and has been translated in over 20 languages. Initially the tool was only used among inpatient cancer palliative care units.</p>	<p>Identification of the ESAS as a longitudinal study for assessment of symptoms. Over 25 years of use the ESAS has demonstrated that the ESAS offers symptom identification over a period of time. The ESAS-r is an effective tool to assess symptoms at the “now” moment.</p>	<p>Background information on the screening tool.</p>
<p>Wu, H.-L., & Volker, D. L. (2012). Humanistic Nursing Theory: application to hospice and palliative care. <i>Journal of Advanced Nursing</i>, 68(2), 471–479.</p>	<p>To understand the role of nursing theory in palliative care practice, specifically identifying the humanistic nursing theory.</p>	<p>N/A</p>	<p>N/A</p>	<p>N/A</p>	<p>Concepts: moreness-choice, call-and-response, intersubjective transaction, uniqueness-otherness, being and doing and community.</p>	<p>Nursing Theory. The article was published in 2012 but the theory remains active in nursing practice.</p>

https://doi-org.akin.css.edu/10.1111/j.1365-2648.2011.05770.x						
<p>Brooks, J. V., Poague, C., Formagini, T., Sinclair, C. T., & Nelson-Brantley, H. V. (2020). The role of a symptom assessment tool in shaping patient-physician communication in palliative care. <i>Journal of pain and symptom management</i>, 59(1), 30–38. https://doi.org/10.1016/j.jpainsymman.2019.08.024</p>	<p>To identify how caregivers, and patients assess symptoms on the ESAS and analyze communication between patients and caregivers/providers.</p>	<p>Mixed methods study</p>	<p>31 semi-structured interviews. 18 patients were interviewed, and 13 caregivers were interviewed.</p>	<p>N/A</p>	<p>Patients reported the benefit that the ESAS has at prioritizing symptoms prior to meeting with providers. However, patients also reported difficulty completing the tool. Caregivers reported improved prioritization of symptom control after using the ESAS tool.</p>	<p>Outcomes</p>
<p>Hui, D., Meng, Y. C., Bruera, S., Geng, Y., Hutchins, R., Mori, M.,</p>	<p>To identify the ESAS as a common tool to expedite the referral process</p>	<p>Systematic Review</p>	<p>186 publications</p>	<p>N/A</p>	<p>There are several tools to screen end stage cancer, terminal illness, or distress, but</p>	<p>Interventions</p>

<p>Strasser, F., & Bruera, E. (2016). Referral criteria for outpatient palliative cancer care: A systematic review. <i>The oncologist</i>, 21(7), 895–901. https://doi.org/10.1634/theoncologist.2016-0006</p>	<p>to outpatient palliative care clinics and ensure standardized care among patients.</p>				<p>often referral to outpatient palliative care clinics is based on patient preference rather than the patient's disease progression.</p>	
<p>Diplock, B. D., McGarragle, K. M. C., Mueller, W. A., Haddad, S., Ehrlich, R., Yoon, D.-H. A., Cao, X., Al-Allaq, Y., Karanicolas, P., Fitch, M. I., Myers, J., Mitchell, A. J., & Ellis, J. W. M. (2019). The impact of automated screening with Edmonton</p>	<p>To assess patient reports of HRQoL and patient satisfaction of care (PSC) based on results of the ESAS.</p>	<p>Pre-post study</p>	<p>268 participants</p>	<p>Two groups of participants were screened: one without the ESAS tool and one with the ESAS tool.</p>	<p>Patients who were administered the ESAS reported higher HRQoL, and PSC. Lower ESAS scores also demonstrated improved HRQoL. Those who were not administered the ESAS were more out of touch with their symptom management and thus did not</p>	<p>Outcome Measure. Supportive Care in Cancer Journal</p>

<p>Symptom Assessment System (ESAS) on health-related quality of life, supportive care needs, and patient satisfaction with care in 268 ambulatory cancer patients. <i>Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer</i>, 27(1), 209–218. https://doi-org.akin.css.edu/10.1007/s00520-018-4304-0</p>					consistently report HRQoL, or PSC.	
<p>Tanco, K., Vidal, M., Arthur, J., Delgado Guay, M., Hui, D., Liu, D., . . . Bruera, E. (2018). Testing</p>	<p>To identify the ways in which the ESAS will assess caregiver burden and ability for</p>	<p>Prospective Study</p>	<p>90 participants - patient and patient caregiver duo</p>		<p>The ESAS was found to be a feasible tool for caregivers to use. 90/90 caregivers completed the</p>	<p>Background information.</p>

<p>the feasibility of using the Edmonton Symptom Assessment System (ESAS) to assess caregiver symptom burden.</p> <p><i>Palliative and Supportive Care, 16(1), 14-22.</i> doi:10.1017/S1478951517000098</p>	<p>symptoms to be recognized and appropriately treated by caregivers.</p>				<p>ESAS tool during the study. 100% of participants completed more than 9 out of the 12 questions on the ESAS, and 66/90 or 73% of participants found the ESAS as a useful tool.</p>	
<p>Lage, D. E., Nipp, R. D., D'Arpino, S. M., Moran, S. M., Johnson, P. C., Wong, R. L., Pirl, W. F., Hochberg, E. P., Traeger, L. N., Jackson, V. A., Cashavelly, B. J., Martinson, H. S., Greer, J. A., Ryan, D. P., Temel, J. S., & El-Jawahri, A. (2018).</p>	<p>To examine the predictors of discharge among end of life patients</p>	<p>Prospective, quantitative study</p>	<p>932 patients</p>	<p>During admission the patients physical symptoms were assessed using the ESAS tool and psychological distress was measured using the Patient Health Questionnaire-4.</p>	<p>Patients who were discharged to postacute care or hospice were more likely to have higher ESAS scores. Further, patients who were discharged to postacute care rather than to hospice had lower survival rates. The ESAS is a predictor of</p>	<p>Implementation</p>

<p>Predictors of posthospital transitions of care in patients with advanced cancer. <i>Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology</i>, 36(1), 76–82. https://doi-org.akin.css.edu/10.1200/JCO.2017.74.0340</p>					<p>discharge disposition.</p>	
<p>Nakazawa, Y., Sakashita, A., Kaizu, M., Abo, H., Ise, Y., Shinada, Y., Sugano, K., Yamashiro, A., Akizuki, N., & Kato, M. (2020). A self-check program targeting quality improvement in a hospital-based</p>	<p>To identify how the Plan, Do, Check, Act cycle can help increase the number of palliative care consults in the hospital setting.</p>	<p>Retrospective study, QI project in Japan.</p>	<p>N/A</p>	<p>Utilization of the PDCA model in the roll out of QI project.</p>	<p>The PDCA cycle was foundational to the evaluation process of this QI project. From the PDCA process, researchers were able to make changes to the project along the way. For example, increased education for certain</p>	<p>Conceptual framework</p>

<p>palliative care consultation team, Japanese society for palliative medicine: Issues regarding team activities identified through the plan-do-check-Act cycle. <i>Journal of Palliative Medicine</i>, 23(3), 359–367. https://doi-org.akin.css.edu/10.1089/jpm.2019.0236</p>					<p>departments with high acuity patients.</p>	
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Appendix B

Objective	Prior to IRB Approval	Month 1	Month 2	Month 3
1. DNP Student will create a pre and post survey for current hospice caregivers to evaluate comfort level of pain assessments prior to IRB approval	Work with hospice organization leadership to create pre- and post-survey material			
2. The DNP student will disseminate the pre survey and to patients and/or informal caregivers within the first month of the project implementation.		Administer pre-survey to eligible informal caregivers and/or hospice patients		
3. The DNP student will create an educational pamphlet to educate caregivers on the ESAS tool prior to IRB approval.	Work with stakeholders at hospice organizations to create ESAS education for informal caregivers			

<p>4. The DNP student will offer the educational pamphlet to patients and/or informal caregivers during the first month of the project, during pre-survey collection.</p>		<p>DNP student will offer educational pamphlet to informal caregivers during initial meeting and after pre-survey data collection</p>	<p>DNP student will monitor which patients have received pre-survey and ESAS education and follow up with post-survey</p>	
<p>5. The DNP student will disseminate the post-intervention survey to patients and/or informal caregivers and patients during the third, and final month of the project.</p>			<p>DNP student will follow up with informal caregivers to administer post-survey</p>	
<p>6. The DNP student will collect data from the pre and post surveys and compare results to determine whether project goals have been met in the</p>				<p>DNP student will analyze data and compare pre and post results</p>

third month of the project.				
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Appendix C

Logic Model: Project Implementation Plan

Inputs	Constraints	Activities	Outputs	Short Term	Long Term	Impact
Facility Staff <ul style="list-style-type: none"> ● Admissions Team ● PCC/SW ● Project Lead 	Time	Meetings	Number of caregivers educated	ESAS knowledge improvement	Improved assessment at the end of life	Decreased caregiver role strain
Materials (ESAS Education tool, Pre/Post Survey)	Impending mortality	Training	Amount of education delivered	Post-Survey improvement in knowledge and confidence	Increased awareness of end of life symptoms	Increased patient QOL
Physical location	Grief	Post-survey	Symptom severity monitored	Increased ESAS utilization	Quicker time to intervene to new onset symptoms at the end of life	Increased confidence in assessment of symptoms at the end of life
Computer resources (Intellectus Statistics)	Lack of interest in education	Staff ESAS education				
Caregiver participants						

Appendix D

ESAS Pre-Survey

For questions 1-3, please refer to the following 1-5 scale:

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

1. On a scale of 1-5 how comfortable do you feel assessing end of life symptoms in yourself/your loved one? Please circle your score.

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

2. On a scale of 1-5 how comfortable do you feel responding to end of life symptoms in yourself/your loved one? Please circle your score.

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

3. On a scale of 1-5 how familiar would you say you are with understanding end of life symptoms within yourself/your loved one? Please circle your score.

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

4. Do you currently use a resource/tool to determine if you/your loved one is experiencing pain or discomfort?

Yes: _____ (if so, please list the resources) _____

No: _____

Completion and return of this questionnaire is an indication of your voluntary consent to participate in this study.

Appendix E

ESAS Post-Survey

For questions 1-3, please refer to the following 1-5 scale:

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

1. On a scale of 1-5 how comfortable do you feel assessing end of life signs and symptoms in yourself/your loved one after completing education on the ESAS tool?

Please circle your score.

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

2. On a scale of 1-5 how comfortable do you feel responding to end of life signs and symptoms in yourself/your loved one after completing education on the ESAS tool? Please circle your score.

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

3. On a scale of 1-5 how familiar would you say you are with understanding end of life signs and symptoms after completing education on the ESAS tool?

Please circle your score.

1= Not at all 2= Somewhat 3= Neutral 4= Mostly 5= Extremely

4. In the past week, how many days did you use the ESAS tool to assess signs and symptoms of your loved one?

Never 1-2 days 2-4 days 5-6 days Everyday

5. In the past week, how many days did you intervene to treat end of life symptoms based on the ESAS score of yourself/your loved one?

Never 1-2 days 2-4 days 5-6 days Everyday

6. In the past week, how many days did you choose not to use the ESAS tool due to time restraints?

Never 1-2 days 2-4 days 5-6 days Everyday

Appendix F



Edmonton Symptom Assessment System (ESAS) Education

Post-Survey: After getting familiar with the ESAS tool, please scan this code through the camera on your phone and complete the post-survey.
Thank you!

Edmonton Screening Assessment System (ESAS)

Purpose: A tool that patients and caregivers can utilize to rate the severity of ten common symptoms:

- Pain
- Drowsiness
- Appetite
- Depression
- Wellbeing
- Tiredness
- Nausea
- Shortness of breath
- Anxiety
- Constipation

The ESAS determines the severity of symptoms at one point in time, but can be tracked over time to monitor trends in patient status.

When to use ESAS: Daily or as often as necessary to assess for changes in signs and symptoms of pain and discomfort.

Who can complete the ESAS: Patients, Caregivers, hospice staff.

What the results mean: Scores can be kept with the patient and/or caregiver to help trend data and promote early recognition of changes over time.

Please circle the number that best describes:

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

Not drowsy 0 1 2 3 4 5 6 7 8 9 10 Worst possible
drowsiness
(feeling sleepy)

Best appetite 0 1 2 3 4 5 6 7 8 9 10 No appetite at all

Not depressed 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression
(feeling sad)

Best wellbeing 0 1 2 3 4 5 6 7 8 9 10 No wellbeing
(overall feeling)

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible
tiredness
(lack of energy)

Not nauseated 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea

No shortness of 0 1 2 3 4 5 6 7 8 9 10 Worst possible SOB
breath (SOB)

No anxiety 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety
(feeling nervous)

No constipation 0 1 2 3 4 5 6 7 8 9 10 Worst possible

Patient's Name _____

Completed by (check one) Patient ___ Caregiver ___ Staff ___

Date _____ Time _____ Patient _____

Please circle the number that best describes:

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

Not drowsy 0 1 2 3 4 5 6 7 8 9 10 Worst possible
drowsiness
(feeling sleepy)

Best appetite 0 1 2 3 4 5 6 7 8 9 10 No appetite at all

Not depressed 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression
(feeling sad)

Best wellbeing 0 1 2 3 4 5 6 7 8 9 10 No wellbeing
(overall feeling)

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible
tiredness
(lack of energy)

Not nauseated 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea

No shortness of 0 1 2 3 4 5 6 7 8 9 10 Worst possible SOB
breath (SOB)

No anxiety 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety
(feeling nervous)

No constipation 0 1 2 3 4 5 6 7 8 9 10 Worst possible
constipation

Patient's Name _____

Completed by (check one) Patient ___ Caregiver ___ Staff ___

Date _____ Time _____ Patient _____

Adapted from: Cancer Care Ontario. (2010) Edmonton Symptom Assessment System. Retrieved from
http://cancercaresoutheast.ca/sites/default/files/files/resource/edmonton_symptom_assessment_system.pdf

Examples of symptoms in each category:

Pain: Expressing pain, discomfort, burning, soreness, or hurting sensation

*Nonverbal: Facial expressions such as: furrowed eyebrows, facial grimacing, clenched jaw, grasping or clutching surroundings, rigid body, flinching when touched, guarding area of the body or resisting being touched, moaning, irritability

Drowsiness: Feeling tired, or fatigued

*Nonverbal: Difficulty keeping eyes open, cannot hold conversation, difficult to arouse

Appetite: Not feeling hungry, little interest in fluids and foods

*Nonverbal: Refusing to take a bite of food, eating very few bites of food, weight loss

Depression: Feeling hopeless, and/or tearful

*Nonverbal: Withdrawal of conversation, lack of conversation, purposeful engagement in self-harming behaviors

Wellbeing - mostly subjective category meaning you should use your best judgment to determine if the patient is feeling well or unwell

*Nonverbal: Overall appearance of comfort

Tiredness: Lack of energy

*Nonverbal: Sleeping often

Nausea: Feeling like you may vomit

*Nonverbal: Vomiting and retching

Shortness of breath: Feeling short of breath, feeling anxious

*Nonverbal: Gasping for air, appears to be breathing faster, nasal flaring, noisy breathing, skin appears to be more blue, skin feels cold

Anxiety: Feeling nervous, on edge, anxious, fast heart beat, or short of breath, short tempered, tearful

*Nonverbal: Picking at the sheets, difficulty sleeping, picking at skin, sweating, nausea

Constipation: Abdominal or rectal discomfort, difficulty passing stool, bloating

*Nonverbal: Signs of pain, anxiety, and knowledge of previous bowel movements