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# Pain in the Dying Patient

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Pain in the Dying Patient

A Paper Submitted in Partial Fulfillment of the Requirements

For NURS 5382: Capstone

In the School of Nursing

The University of Texas at Tyler

by

Shanna Selph, BSN, RN

August 3, 2023

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#### Acknowledgments

I would like to take this time to thank everyone who has helped me throughout my educational journey. Thank you, Dr. Colleen Marzilli, for providing guidance, constructive criticism, and grace during this project. Your grace was greatly appreciated as it allowed me to find balance in finishing this project. This project would not be completed without you. You have been a great resource throughout my time as a student in the Master of Science Nursing program. I would also like to thank Dr. Patricia Wilson for her one-on-one time to review improvements that could be made regarding my project. I also want to take the time to thank my children, Sage and Lucas, who have been so understanding of me being in school for an extended amount of time to better our lives. Finally, I would like to thank God for allowing me to have all of this and continuing my success, without God, none of this would have been possible.

#### **Executive Summary**

This benchmark aims to educate nurses, doctors, and families on the importance of proper pain management in dying patients. The evidence in this benchmark will be appraised to improve practice, improve outcomes, and reduce healthcare costs (Melnyk, 2018). Feelings of being overwhelmed, fatigue, confusion, and guilt can occur in healthcare professionals without the proper knowledge of pain in the dying patient. Health professionals are responsible for ensuring proper care of patients is taken during the most difficult time of their lives to ensure they have the best quality of life through the end of their lives. The question to be answered is, In the dying patient, how does managed pain compared to unmanaged pain affect the quality of life during the end of life?

A proposal to be implemented is a benchmark detailing the use of continuous subcutaneous infusions and oral opioids once a patient is actively dying. This benchmark details how pain is unmanaged at the end of life and why change is necessary. Opioids have been shown to improve pain and shortness of breath during death. Since opioids have been shown to be effective, this should be implemented for hospice patients in the hospital setting to ensure symptom management with medication schedules. Data to prove why a change is necessary is the prevalence of patients in pain daily during the last thirty days of life, reports from caregivers or family members detailing symptoms the last week of life, the family's perception of quality at the end of life, data detailing patient's place of death if pain medication was used, what route the medication was administered, and data determining if an end of life conversation occurred prior to death. The current pain medication regimens that are in place now are not acceptable means of treating a patient in pain at the end of life due to their ineffectiveness and hesitancy in healthcare using the current regimens in place. The current pain regimens that are in place at many companies are:

Morphine 20 mg/1 mL, 1 mL PO/SL Q1H PRN pain or SOB Ativan 1 mg, 1 tab PO Q4H PRN anxiety or restlessness Tylenol 650 mg rectal suppository, 1 rectal suppository Q6H PRN fever > 101 F Zofran ODT 4 mg, 1 tab PO/SL Q4H PRN nausea or vomiting. Bisacodyl 10 mg rectal suppository, 1 rectal suppository Q12H PRN constipation Hyoscyamine 0.125 mg, 1 tab PO/SL Q4H PRN secretions

This is the common comfort kit in place to manage pain at the end of life. If there is an increase in the usage of these medications, then new orders are received from the MD to put the patient on a longer-acting opioid to manage pain. This must change as statistics show most patients die in pain at the end of life.

#### **Rationale for the Project**

Pain in the dying patient is an important issue for healthcare because nurses are seeing an increase in dying patients due to the impact of the pandemic of Covid-19. Deaths in the United States increased by 19% between 2019 and 2020 following the onset of the COVID-19 pandemic in March 2020 — the largest spike in mortality in 100 years (Bureau, 2022). With deaths rising, an important question of whether pain in dying patients is being managed at the end of life became apparent. As a hospice nurse, it became evident some hospice medical directors still consider the effects of pain medications following the guidelines of the typical healthy person and limiting pain medications in the dying patient. Symptom management remains a critical

challenge at the end of life and is central to good end-of-life care, yet not all patients have their symptoms adequately controlled (Gerber, 2022). The number one goal for healthcare professionals for patients at the end of life should be to provide quality of life. This is achieved by providing comfort. In the final days, weeks, and months, patients should connect with loved ones and reflect on life instead of suffering from pain (HealthDay, 2019). If pain in the dying patient is not addressed, this will lead to more patients dying with unrelieved pain and without quality at the end of life which can lead to complicated grief for family members after the patient has died.

### Literature Synthesis.

Lack of knowledge, underdeveloped end-of-life pathways, delays in referrals to palliative care due to bias, healthcare settings, and lagging skills are causing patients to die with pain at the end of life (Chan et al., 2016; Fürst et al., 2020; Van Den Block et al., 2020; Hagarty et al., 2020; Klint et al., 2019; Sandvik et al., 2016; Schelin et al., 2018; Su et al., 2018). Patients who die in a hospital setting are at a statistically higher risk of dying with unrelieved pain. The setting in which a patient dies should be calming and peaceful. Specialized palliative care pathways with the use of opioids along with training to improve new knowledge and new skills need to be better integrated into the hospital setting because it has been proven to provide a better quality of life to patients at the end of life (Fürst et al., 2020; Dietrich et al., 2015; Van Den Block et al., 2020; Hagarty et al., 2020; Klint et al., 2019; Schelin et al., 2018; Su et al., 2018). Palliative care pathways to improve staff knowledge alone did not indicate a clinically relevant improvement and required the intervention of using opioids to relieve pain at the end of life for patients (Chan et al., 2016; Fürst et al., 2020; Van Den Block et al., 2020). Most pain can be diminished with the appropriate use of analgesic medications by having the nurse provide frequent pain

assessments on a scheduled interval (Mercadante et al., 2009; Moyniham, 2003). Multiple interventions have reflected the reduction of pain in dying patients at the end of life and improved quality of life, but two common themes affecting pain have been identified: the hospital setting and the need to use opioids to include a continuous subcutaneous infusion with oral opioids with the emphasis on the need for training to improve knowledge and skills. Hospitals are a primary source of healthcare. Not providing appropriate education and training to healthcare workers to prepare them for the dying patient is an injustice to the patient and the family.

#### **Project Stakeholders**

Stakeholders would be the patient, the patient's family or caregivers, physicians, nursing staff, social worker, chaplain, volunteers, the executive director of the hospice company, the CNO of the hospital, the CEO of the hospital, and the department head of the medical surgical floor the patients would be assigned to while in the hospital. Inter-professional involvement would include nurses, certified nursing assistants (CNA), chaplains, and physicians working together to ensure all elements of the patient's needs are being met to ensure quality and symptom management control at the end of life. Management teams would also be necessary to implement strict protocols to prevent skewed results of this change project. Permission will need to be obtained from the executive director of the hospice company along with the CNO and CEO of the hospital, as they are the gatekeepers of this change project. The change champions will be the nurses implementing this change as they are the ones evaluating the effectiveness of medications used and if symptoms are managed. Other personnel to help as change champions are the CNAs who may see the patient more frequently than the nurse.

### **Implementation Plan**

There are several major steps in the implementation process for this change project.

Major phases of implementation include pre-clinical training, simulation, and then transition to clinical at the bedside where new knowledge and skills can be implemented.

- Weeks 1-2: All stakeholders and healthcare providers attend training with a specialized palliative care team to improve knowledge and skills pertaining to end-of-life care.
- Weeks 3-4: All stakeholders and healthcare providers would attend a simulation with the specialized palliative care team to understand how medication administration would occur with the continuous subcutaneous infusion and oral medications, and how to recognize nonverbal signs of pain.
- Weeks 5-12: Stakeholders and healthcare providers would be in the hospital setting providing assessments of the patients, administering the medications needed to provide symptom management at the end of life, and ensuring quality.

#### **Timetable/Flowchart**

The timetable for this project to be implemented would be PICOT question development, evidence-based practice research, developing a change project, implementing a benchmark study, and finally delivering the benchmark to upper management to support this change. Throughout this benchmark, there will be a process in which this should be implemented. During the beginning of this benchmark during weeks 1-2 specialized palliative care teams will be in place to provide specialized education to the staff or stakeholders who would be implementing this benchmark. During weeks 3-4, all individuals will begin simulation training with subcutaneous pain medication pumps and oral pain medication delivery. During weeks 5-12 staff will be present in a hospital clinical setting implementing this project and evaluating the

effectiveness of the new regimen during it being carried out.

Timeframe	Weeks 1-2	Weeks 3-4	Weeks 5-12			
Process	All stakeholders and healthcare providers attend training with a specialized palliative care team to improve knowledge and skills pertaining to end-of- life care.	All stakeholders and healthcare providers would attend a simulation with the specialized palliative care team to understand how medication administration would occur with the continuous subcutaneous infusion and oral medications, and how to recognize nonverbal signs of pain.	Stakeholders and healthcare providers would be in the hospital setting providing assessments of the patients, administering the medications needed to provide symptom management at the end of life, and ensuring quality.			
Interventions	<ul> <li>Education on signs and symptoms of End of Life</li> <li>Education on the process of End of Life</li> <li>Education on signs and symptoms of pain</li> <li>Education on pain medications and their effects</li> </ul>	<ul> <li>Multiple simulation sessions in the lab with different scenarios</li> <li>All supplies would be provided in this simulation lab</li> </ul>	<ul> <li>Evaluation tools will be used to evaluate effectiveness of regimen.</li> <li>Data will be collected during this time period.</li> </ul>			

#### **Data Collection Methods**

The data needed to determine if the change was successful will be patient assessments prior to death along with family surveys about care post-death. The purpose of the surveys is to assess the effectiveness of the pain regimen and the basis of this change project. If the change cannot be enacted, frequent assessments by the hospice nurse would need to be conducted to assess the need for a change in the medication regimen to provide efficient symptom management. Once the surveys were analyzed, an interdisciplinary team meeting would occur to discuss the outcome of the change project. Important topics to discuss in the meeting would be the perception of the staff of the launch of the intervention, how did staff perceive the actual intervention, were any changes needed throughout the change project, did the staff feel heard, did staff receive proper education or training, did staff feel knowledgeable on the topic of the benchmark, and if the benchmark made a difference in patients' quality of life? The outcome of this benchmark would be to successfully control every patient's pain at the end of life. Ways to know the intervention is successful is frequent pain assessments including staff observation and providing questionnaires to the family after their family members have passed away.

#### **Cost/Benefit Discussion**

The associated costs would be minimal as comfort medications provided at the end of life are covered by most health insurance plans. However, other associated costs would be a contract to be implemented between a hospice company and a hospital when care is implemented by a hospice company inside a hospital, equipment needed to maintain comfort for the patient listed above, salaries of the personnel carrying out the change project, training for the personnel involved in the change project, and the hiring of a specialized palliative care team to provide education to healthcare providers involved in this benchmark. This intervention can be justified by the reduction in the cost of the use of multiple different pain medications and ambulance trips that would occur if the pain was not properly managed from the beginning of the pain beginning.

#### **Discussion of Results**

I was not able to implement this project as I became PRN at the location this would have been implemented in. Some consideration as to why this would not have been implemented is not being able to overcome the barrier of overmedicating with pain medications. The stigma of pain medications is still very prevalent. Overcoming the stigma that is associated with pain medications will require a longer time frame to be able to implement proper education as to why more pain medication is needed at the end of life.

#### **Conclusions/Recommendations**

Through the referenced articles this benchmark has detailed the statistics of patients who had unrelieved pain at the end of life. Two significant themes were identified with an emphasis on the need for training to improve knowledge and skills: the hospital setting and the need for continuous subcutaneous infusions along with oral opioids compared in relation to their significance in the management of pain at the end-of-life. A new protocol could be established for managing pain in the dying patient with the initiation of this benchmark and an interprofessional team in place. Although there has been substantial discussion in this benchmark, more research needs to be conducted to gather data and information to better serve patients at the end of life. Detailed feedback derived from dying patients, their families, and their interprofessional teams with firsthand experience and knowledge of the challenges outlined here will greatly impact the quality of life for patients that are at the end of life.

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# PAIN IN THE DYING PATIENT Appendix A

# Synthesis Table

Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION
(Study #1) Chan, 2016, End-of- life care pathways for improving outcomes in caring for the dying	To assess the effects of end-of- life care pathway, compared with usual care	Standard methodologi cal procedures used by Cochrane Database	Systemat ic review	We included patients and carers/fa milies who had received care guided by an end-of- life care pathway.	There was very low- quality evidence of a difference in overall control of breathlessness that favored the Liverpool Care Pathway group compared to usual care: the study reported an odds ratio (OR) of 2.0 with 95% confidence intervals (CIs) 1.1 to 3.8. Very low- quality evidence of no difference was found for pain (OR 1.3, 95% CI 0.7 to 2.6, P = 0.461) and nausea and	None of the other primary outcomes were assessed by the study.	Liverpool Care Pathway	We screened 3028 titles and included one Italian cluster RCT with 16 general medicine wards (inpatient units in hospitals) and 232 carers of cancer patients in this updated review. We judged the study to be at a high risk of bias overall, mainly due to a lack of blinding and rates of attrition. Only 34% of the participants (range 14% to 75% on individual wards) were cared for in accordance with the care pathway as planned.	<ol> <li>Low Quality</li> <li>The Liverpool Care Pathway didn't provide any evidence of a difference in the management of symptoms at the end of life.</li> </ol>

Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION
					vomiting (OR 1.5, 95% CI 0.7 to 3.2, P = 0.252).			However, these issues were to be expected due to the nature of the intervention and condition. The study population was all cancer patients in their last days of life. Participants were allocated to care using the Liverpool Care Pathway (LCP- I, Italian version of a continuous quality improvement programme of end-of-life care) or to standard care. The primary outcomes of this review were physical symptom severity, quality of life, and any adverse effects.	

# PAIN IN THE DYING PATIENT

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Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION		
								Physical symptom severity was assessed as overall control of pain, breathlessness, and nausea and vomiting. There was very low quality evidence of a difference in overall control of breathlessness that favoured the Liverpool Care Pathway group compared to usual care: the study reported an odds ratio (OR) of 2.0 with 95% confidence intervals (CIs) 1.1 to 3.8. Very low quality evidence of no difference was found for pain (OR 1.3, 95% CI 0.7 to 2.6, P = 0.461) and nausea and			

				PAI	N IN THE DYI	NG PATIENT			18
Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION
								vomiting (OR 1.5, 95% CI 0.7 to 3.2, P = 0.252). None of the other primary outcomes were assessed by the study. Limited data on advance care planning were collected by the study authors, making results for this secondary outcome unreliable. None of our other secondary outcomes were assessed by the study.	
(Study #2) Van Den Block, 2020, Evaluatio n of a palliative care program for nursing	To investigat e the effect of the Palliative Care for Older People (PACE) Steps to Success	followed CONSORT guide- lines for cluster trials to design	Randomi zed Control Trial	Nursing homes were approach ed randoml y from a list of all nursing homes in a predefin	Residents' comfort in the last week of life did not differ between intervention and control groups (baseline- adjusted mean difference, -0.55; 95%	We used linear mixed models (LMMs) to analyze continuous outcomes.	PACE Steps to Success Program	Concerning deceased residents, we collected 551 of 610 questionnaires from staff at baseline and 984 of 1178 postintervention in 37 intervention and	<ol> <li>High Quality</li> <li>Staff in the intervention group had statistically significantly better knowledge of palliative care than staff in the control group.</li> </ol>

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Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION
homes in 7 countries: the pace cluster- randomiz ed clinical trial	Program on resident and staff outcomes			ed geograp hical location	CI, $-1.71$ to 0.61; P = .35). Staff in the intervention group had statistically significantly better knowledge of palliative care than staff in the control group, but the clinical difference was minimal (baseline- adjusted mean difference, 0.04; 95% CI, 0.02-0.05; P < .001).			36 control homes. Mean (SD) age at time of death ranged between 85.22 (9.13) and 85.91 (8.57) years, and between 60.6% (160/264) and 70.6% (190/269) of residents were women across the different groups. Residents' comfort in the last week of life did not differ between intervention and control groups (baseline- adjusted mean difference, -0.55; 95% CI, -1.71 to 0.61; P = .35). Concerning staff, we collected 2680 of 3638 questionnaires at baseline and	

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Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION		
								2437 of 3510 postintervention in 37 intervention and 38 control homes. Mean (SD) age of staff ranged between 42.3 (12.1) and 44.1 (11.7) years, and between 87.2% (1092/1253) and 89% (1224/1375) of staff were women across the different groups. Staff in the intervention group had statistically significantly better knowledge of palliative care than staff in the control group, but the clinical difference was minimal (baseline- adjusted mean difference, 0.04;			

PAIN IN THE DYING PATIENT											
Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION		
(Study #3) Hagarty, 2020, Severe pain at the end of life: a populatio n-level observatio nal study	To explore the prevalenc e of clinically significan t pain at the end of life and identify predictors of increased pain.	Pain is prevalent symptom at the end of life and negatively impacts quality of life.	Populati on-level observati onal study	Populati on included all decedent in Ontario, Canada from April 1, 2011 to March 31, 2015 who received a Resident Assessm ent Instrume nt – Home Care (RAI- HC) assessme	Adjusting for multiple covariates as listed in our methods, females had greater odds of having severe daily pain [OR = 1.25; 95% Confidence Interval (CI): 1.16 to $1.35$ ] (Table 5). The odds ratio of severe daily pain was 0.31 in the decedents aged 90+ compared to 0-49 (95% CI: 0.23 to 0.42). Those with severe or	We examined the proportion of severe daily pain re- ported in the last 30days of life using population- based administrative databases. We observed that less than 1 in 5 decedents (17.2%) report severe daily pain. This level of pain is considered inadequately treated and would likely be associated with lower quality of life and functional	Logistic Regression Models for Odds of Severe Daily Pain and RAI-HC	95% CI, 0.02- 0.05; P < .001). Data analyses began on April 20, 2018. Pain is a common fear of those contemplating end of life, but severe pain is reported in less than 1 in 5 of our population in the last month of life. Certain subpopulations may be more likely to report severe pain at the end of life and may benefit from earlier palliative care referral and intervention.	<ol> <li>Observational</li> <li>Interventions were not implemented but were detailed to be implemented for change.</li> </ol>		
				last 30 days of life.	cognitive impairment had an OR of	38]. We identified multiple					

PAIN IN THE DYING PATIENT											
Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION		
					0.68 and 0.52, respectively, compared to those who were cognitively intact. When examining disease trajectory, compared to frailty, those with terminal illness were more likely to report severe daily pain (OR 1.66, (95% CI: 1.46 to 1.88). Decedents with designated palliative home care had greater odds of increased pain com- pared to those without [OR 1.13 (95% CI: 1.03 to 1.24)]. Conversely, the trend seen	demographic, clinical and system factors associated with increased end- of-life pain, many of which have not been previously described. Notably, disease trajectory impacted reported severe daily pain at the end of life.					

PAIN IN THE DYING PATIENT											
Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION		
					with physician home visits was no longer statistically significant for specialist or non-specialist home visits when all covar- iates were accounted for [OR 1.12 (95% CI: 0.99 to 1.26) and 1.14 (95% CI: 0.91 to 1.44)].						
(Study #4) Schelin, M., 2018, Quality of care for the dying across different levels of palliative care developm ent: A populatio n based	There is a lack of knowledg e about how the provision and availabilit y of specialize d palliative care relates to the quality	Statistical analysis	Populati on based cohort study	Patients from the Swedish Register of Palliativ e Care (SRPC).	Only two of the five indicators, artificial nutrition/fluid in the last 24 h of life (15.3% vs 17.7%) and not having an EoL conversation (38.7% vs 43.2%), scored better in the fully developed	SRPC End of Life Questionnaire	European Association for Palliative Care (EAPC) Atlas of Palliative Care in Europe9 and the '2015 Quality of Death Index',1	The overall quality of care during last week of life was not consistently better in the region with fully developed palliative care compared with the less developed region. In fact, for patients dying in hospitals and	<ol> <li>Statistical analysis is descriptive.</li> <li>The overall quality of care during last week of life was not consistently better in the region with fully developed palliative care compared with the less developed region.</li> </ol>		

Citation: Author,	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables	Measurement of Major	Data Analysis	Study Findings	Worth to Practice: LOE
Date of Publ. & Title					Studied and Their Definitions	Variables			Strengths/Weaknesses Feasibility Conclusion
									RECOMMENDATION
cohort study	of dying in hospital and communi ty-based settings.				region. By contrast, the proportion of patients lacking an oral health assessment and lacking a pain assessment was very similar between the two regions, and the proportion of patients lacking companionshi p at death was lower in the less developed region (14.9% vs 16.5%).			community- based settings, the quality was statistically significantly better in the less developed region. The small proportion of patients who had access to specialized palliative care had superior quality of care during the last week of life as compared to patients in other care settings.	
(Study #5) Furst, P., 2020, Continuo us subcutane ous infusion for pain	This study aimed to investigat e the effects, and adverse effects, of CSCI for	descriptive study	observati onal cohort study	All Swedish - speaking patients over the age of 18years who were	Both patients with methadone as add-on (MET, n = 13) and patients with only other opioids (NMET, $n =$ 34), improved	Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria	T-tests were used to compare age and survival, and, for other variables, the following non- parametric tests were applied: chi-	CSCI via AIP is an effective way to reduce pain in dying patients without increased adverse effects. Add-on methadone may be beneficial in	<ol> <li>Descriptive statistics</li> <li>Both patients with methadone as add- on and patients with only other opioids, improved in pain control</li> </ol>

## PAIN IN THE DYING PATIENT

Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION
control in dying patients: experienc es from a tertiary palliative care center	pain control in dying patients, with particular interest in methadon e use.			neither sedated nor unconsci ous and who, during daytime (7 am – 8 pm) as part of their regular care, were prescribe d a CSCI of drugs were asked to par- ticipate in the study.	in pain control (p < 0.05 and 0.001, respectively), despite that MET patients had higher pain scores at baseline (p < 0.05) and were on a higher MEDD (240 mg vs.133 mg). No serious adverse effects demanding treatment stop were reported.		square test to compare proportions, Mann– Whitney U test to compare independent groups and Wilcoxon signed-rank test to compare dependent groups.	patients with severe complex pain.	
(Study #6) Klint, 2019. Dying with unrelieve d pain— prescripti on of opioids is	We quantifie d the risk, and investigat ed risk factors, for dying with unrelieve d pain in	Descriptive data analysis	observati onal cohort study.	expected deaths during 2011- 2015	The investigated risk factors included cause of death, place of death, absence of an end-of-life (EoL) conversation,	Swedish Register of Palliative Care (SRPC)	Data are collected using an EoL ques- tionnaire completed after death by one or more mem- bers of the professional team (physician or	Unrelieved pain during the final week of life was reported for 25% of the patients with pain, despite prescription of opioids PRN in 97% of cases. Unrelieved pain	<ol> <li>Descriptive Statistics</li> <li>Unrelieved pain during the final week of life was reported for 25% of the patients with pain, despite prescription of</li> </ol>

## PAIN IN THE DYING PATIENT

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PAIN IN THE DYING PATIENT									
Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION
not enough.	a nationwid e observati onal cohort study.				and lack of contact with pain management expertise		nurse) engaged in the care of the dying patient.	was common both among patients dying of cancer and of nonmalignant chronic diseases. Statistically significant risk factors for unrelieved pain included hospital death (RR 1/4 1.84, 95% CI 1.79e1.88) compared with dying in specialist palliative care, absence of an EoL conversation (RR 1/4 1.42, 95% CI 1.38e1.45), and dying of cancer in the bones (RR 1/4 1.13, 95% CI 1.08e1.18) or lung (RR 1/4 1.10, 95% CI 1.06e1.13) compared with	opioids PRN in 97% of cases.

PAIN IN THE DYING PATIENT									27
Citation: Author, Date of Publ. & Title	Purpose of Study	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Worth to Practice: LOE Strengths/Weaknesses Feasibility Conclusion RECOMMENDATION
								nonmalignant causes.	

# Appendix B

# Flowchart

Timeframe	Weeks 1-2	Weeks 3-4	Weeks 5-12
Process	All stakeholders and healthcare providers attend training with a specialized palliative care team to improve knowledge and skills pertaining to end-of- life care.	All stakeholders and healthcare providers would attend a simulation with the specialized palliative care team to understand how medication administration would occur with the continuous subcutaneous infusion and oral medications, and how to recognize nonverbal signs of pain.	Stakeholders and healthcare providers would be in the hospital setting providing assessments of the patients, administering the medications needed to provide symptom management at the end of life, and ensuring quality.
Interventions	<ul> <li>Education on signs and symptoms of End of Life</li> <li>Education on the process of End of Life</li> <li>Education on signs and symptoms of pain</li> <li>Education on pain medications and their effects</li> </ul>	<ul> <li>Multiple simulation sessions in the lab with different scenarios</li> <li>All supplies would be provided in this simulation lab</li> </ul>	<ul> <li>Evaluation tools will be used to evaluate effectiveness of regimen.</li> <li>Data will be collected during this time period.</li> </ul>

## Appendix C

## **Evaluation Tool**

- 1. Please rate your current pain level on a scale of 0 to 10 with 10 being the worst pain you have ever felt.
- 2. Please rate your worst pain level in the last week on a scale of 0 to 10 with 10 being the worst pain you have ever felt.
- **3.** Please rate your lowest pain level over the last week on a scale of 0 to 10 with 10 being the worst pain you have ever felt.
- **4.** Please rate your average pain level on a scale of 0 to 10 with 10 being the worst pain you have ever felt.
- 5. What makes your pain feel better (for example, heat, medication, rest)?
- 6. What treatments are you receiving for pain?
- 7. In the last week, how much relief have you received from pain treatments or medications that have been provided?
- 8. If you take pain medication, how many hours does it take before the pain returns?
- 9. Circle the adjectives if they apply to your pain:
  - a. Aching
  - **b.** Throbbing
  - c. Shooting
  - d. Stabbing
  - e. Sharp
  - **f.** Tender

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g. Burning

- h. Penetrating
- i. Numb
- j. Cramping
- k. Tiring

**10.** Circle which activities your pain has interfered with in the last week:

- **a.** General activity
- **b.** Mood
- **c.** Walking ability
- d. Normal work (includes outside the home and housework)
- e. Relations with other people
- f. Sleep
- g. Enjoyment of life
- 11. Do you feel you need a stronger type of pain medication?
- 12. Do you feel you need to take more of the pain medication than your doctor has prescribed?
- 13. Are you concerned you use too much pain medication?
- 14. Are you having problems with the side effects of your pain medication?
- 15. Do you feel you need to receive further information about your pain medication?