

# **A Program of Research: Cancer Symptom Management**

**Susan C. McMillan, PhD, ARNP, FAAN**

**Distinguished University Professor**

**Thompson Professor of Oncology Nursing**

***Center for Hospice, Palliative Care***

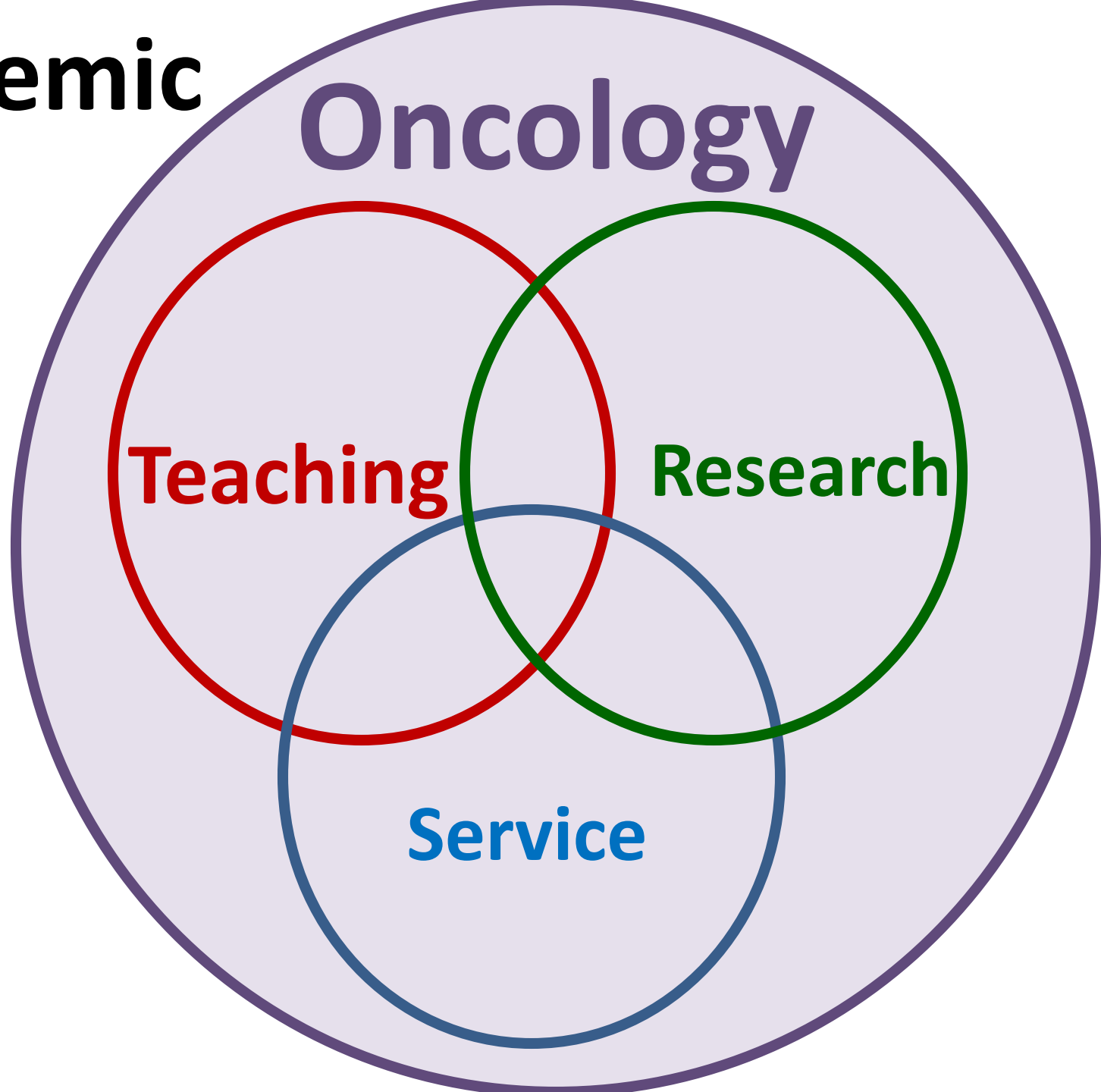
***and End of Life Studies***

**University of South Florida**

**Tampa, FL**



**Academic  
Life**



# The Beginning

**Descriptive studies, largely unfunded provided a foundation.**

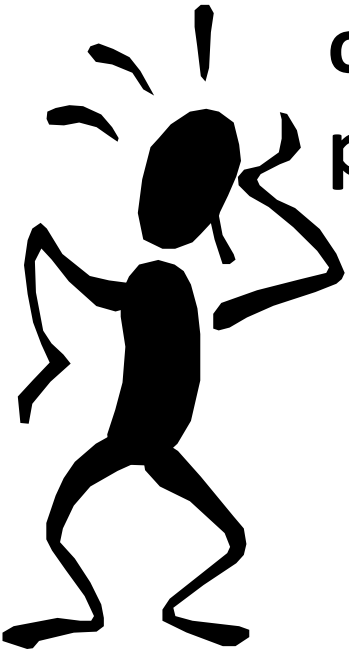


**My first research interest  
was pain management!**



# Descriptive Pain Studies

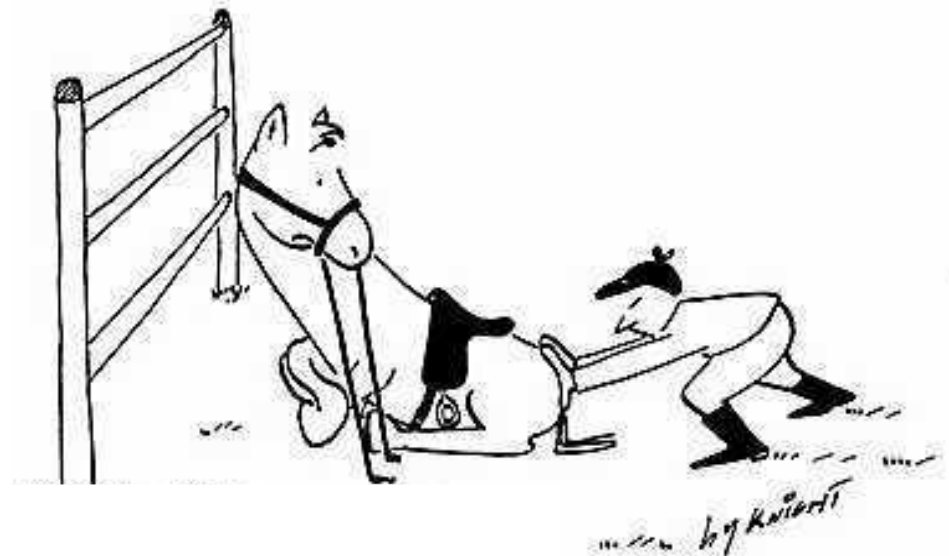
- Conducted in various settings where cancer patients receive care:
  - Pain poorly managed;
  - Patients complain of pain all day;
  - Nurses administer about one third of ordered analgesic while patients still in pain



- Surgical units
- ICUs
- Cancer units
- Hospices

# Moving into Hospice Research

- Hospice Patient Services Committee in '87
- 80% of hospice patients had cancer.
- Persuaded to conduct oncology symptom research beginning in '91 .



# Hospice Outcomes:

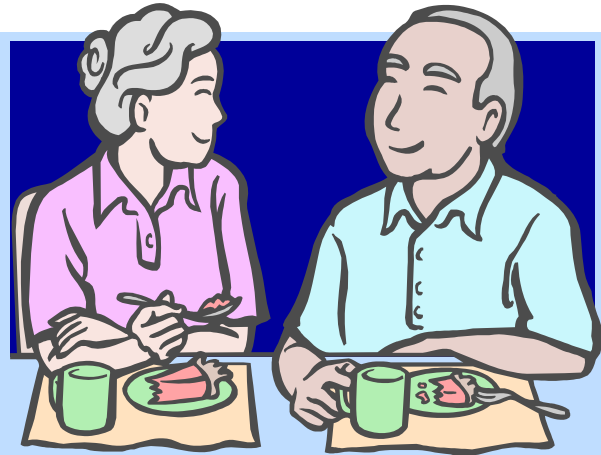
**Improved patient and family  
quality of life!**



# Quality of Life of Patients and Caregivers

- Developed the Hospice Quality of Life Index and
- The Caregiver Quality of Life Index

**Validated instruments on hospice patients with cancer and their family caregivers.**

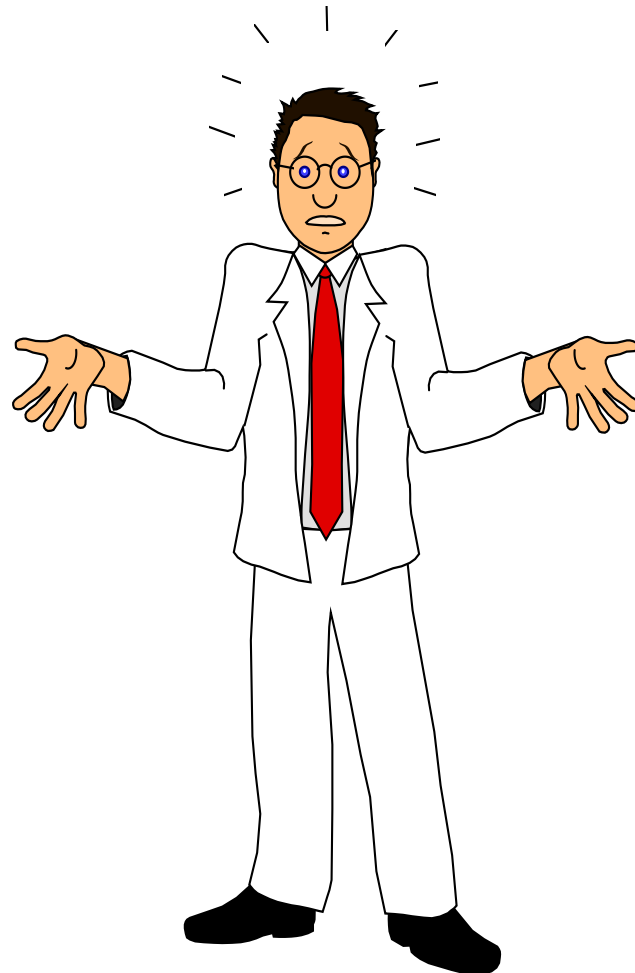


McMillan & Mahon, 1994



**If symptom outcomes are not ideal:**

**Why might this be happening?**

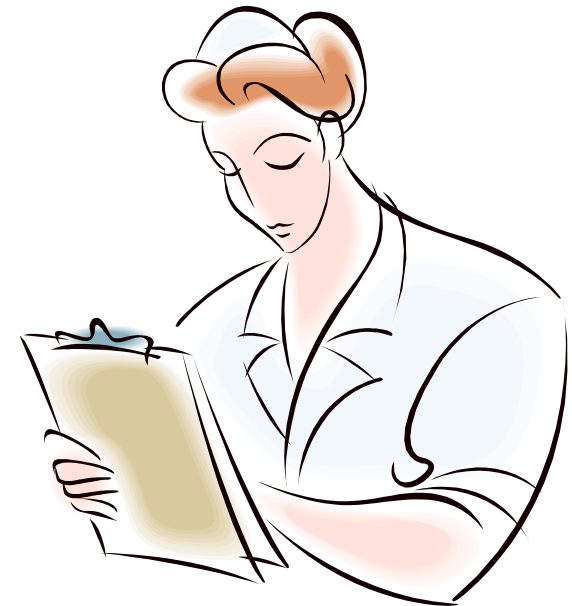
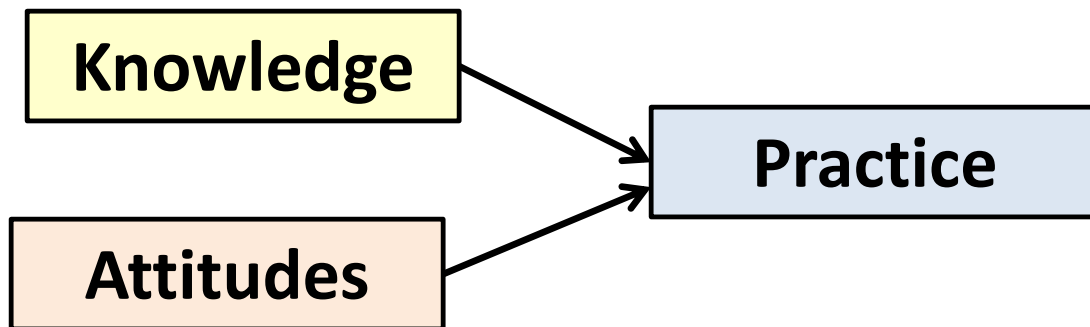


# Nurses' Knowledge and Attitudes

Have a major impact on how pain is managed.

What do nurses know?

What are their attitudes?



VA Funded

# Nurses Knowledge and Attitudes

Have a major impact on how pain is managed.

What do nurses know?

What are their attitudes?

**N=85 nurses working in units where cancer patients were receiving care**



# Knowledge About Pain Management (n=85)

- Range of scores 21-81%
- Mean score 61%

Nurses knew least about:

- Physiology of pain
- Pharmacology of analgesics
- Treatment goals
- Non-pharmacologic methods



# Attitudes About Pain Management

## (n=85 nurses)

- Disagreed that a around the clock dosing is better; 84%
- Agreed that around the clock dosing increases risk for sedation and respiratory depression; 82%
- Agreed that Doctor or nurse assessment more valid than patient assessment of pain. 51%



# Attitudes About Patients in Pain

(n=85 nurses)

**In a 25 y.o. man post-op day 1 reporting pain of 8 (0-10):**

- **Would reduce dose of analgesic if patient laughing with visitors** **59%**
- **Would allow concerns about addiction, tolerance, dependence or respiratory depression to change the amount of analgesic given from what was ordered;** **41%**
- **If man was grimacing in pain, but had stable vital signs, would reduce the dose or give no analgesic even though it was ordered.** **46%**

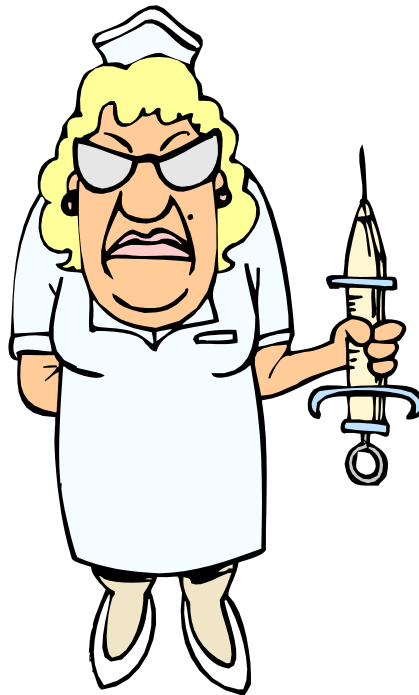
# Attitudes About Patients in Pain (n=85)

If man was older (72 years) and c/o pain of 8 (0-10 scale):

- Would reduce dose of analgesic below what was ordered; 63%
- Would allow concerns about addiction, tolerance, dependence or respiratory depression to change the amount of analgesic given; 58%



**How did that translate into pain management by these same nurses?**





# Pain Relief in Hospitalized Cancer Patients

(n=90)

## METHODS:

- Admitted for  $\geq 48$  hours:
- Pain assessed 3X in 24 hours to get daily mean;
- VAS – 0-100 for pain intensity



McMillan et al., 2000

# Pain Relief in Hospitalized Cancer Patients (n=90)

## RESULTS:

- Daily pain:
  - Range = 0-98
  - Mean = 32.5
  - SD = 25.3
- Patients often under-medicated for pain;
- Patients with very high daily VAS received no pain medication;



# **Knowledge About Pain Management**

## **REPEATED (n=41)**

- **Range of scores 39-81%**
- **Mean score 63%**

**Only 17% of nurses had scores higher than 70%  
(F grade)**

**Nurses knew least about:**

- **Physiology of pain**
- **Pharmacology of analgesics**
- **Treatment goals**

# Attitudes About Pain Management

**REPEATED** (n=41 nurses)

- Disagreed that a around the clock dosing is better;
- Agreed that around the clock dosing increases risk for sedation and respiratory depression;
- Agreed that patients in pain can tolerate higher doses of opiates without sedation or respiratory depression.

95%

15%



# Pain is not the only symptom!

(n=275 hospice patients with cancer)

## **SYMPTOM:**

## **PERCENT**

• Fatigue	83
• Pain	73
• Dry mouth	71
• Drowsiness	60
• Loss of appetite	56
• Shortness of Breath	55

# Pain not the most severe symptom!

(n=275 hospice patients with cancer)

## **SYMPTOM:**

## **Severity\***

- |                       |     |
|-----------------------|-----|
| • Fatigue             | 6.8 |
| • Loss of appetite    | 6.3 |
| • Constipation        | 6.3 |
| • Shortness of Breath | 6.0 |
| • Difficulty Sleeping | 6.0 |
| • Pain                | 5.8 |

**\* 0-10 scale**

McMillan & Rivera, 2009

# Pain not the most distressing symptom!

(n=275 hospice patients with cancer)

<b>SYMPTOM:</b>	<b>Distress*</b>
• Fatigue	6.8
• Loss of appetite	6.3
• Constipation	6.3
• Difficulty Sleeping	6.0
• Cough	6.0
• Pain	5.8
• Shortness of breath	5.8

**\*0-10 scale**

McMillan & Rivera, 2009

# Assembled a Team

- Brent Small, PhD, Aging Studies (1,2,3,4,5)
- William Haley, PhD, Aging Studies (1,2,5)
- Cindy Toftthagen, PhD, ARNP, FAAN, Nursing (3,4,5)
- Ronald Schonwetter, MD, Hospice (1, 2)
- Melissa Leggatt, Program Manager (23 years)





# Assembled a Team

- Brent Small, PhD, Aging Studies (1,2,3,4,5)
- William Haley, PhD, Aging Studies (1,2,5)
- Cindy Tomlinson, PhD, Nursing (3,4,5)
- Ronald S. ...



**Melissa Leggatt,  
Program Manager**

# Symptom Management Using COPE

- **Caregivers of cancer patients (NCI)**
- **Caregivers of Heart Failure patients (NINR)**
- **Patients with cancer (PCORI)**
- **Chemotherapy-Induced Peripheral Neuropathy (Toftshagen, PI)**



# COPE Problem-Solving Approach to Cancer Symptom Management

## *Homecare Guide for Cancer*

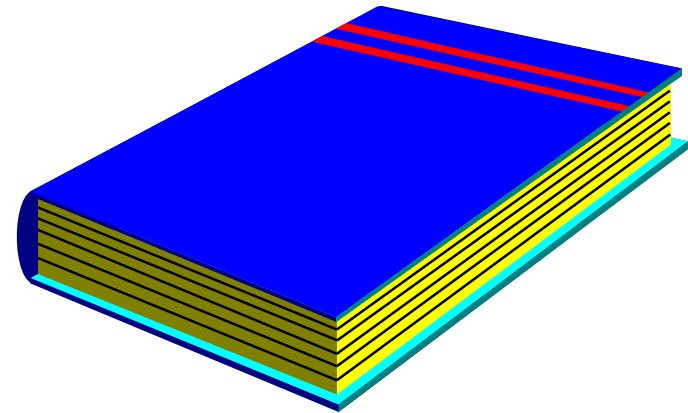
(Houts & Bucher (2012); available through ACS)

**C**reativity

**O**ptimism

**P**lanning

**E**xpert Guidance



# COPE : for Caregivers of Hospice Cancer Patients

- **CG training to support symptom management for patients; this study focused on:**
  - pain,
  - dyspnea, and
  - constipation.
- **Patients too debilitated for intervention;**
- **N=329 patient/caregiver dyads.**



# COPE: for Caregivers of Hospice Cancer Patients

- Apparently one of the first funded projects to collect data directly from patient/caregiver dyads.
- Reviewers not experienced with hospice research; concerned about projected attrition

**Lesson learned:** Justify everything!



# COPE: for Caregivers of Hospice Cancer Patients

## Intervention:

- Three home visits by nurse (45,30,30 minutes each); home health aide stayed with patient;
- Reviewed different **PRIORITY** symptom each visit;
- Applied problem-solving approach to each problem:

**C**reativity

**O**ptimism

**P**lanning

**E**xpert Guidance



# Spouses





# Adult Children





# Results: COPE Intervention for Caregivers

## Caregiver Outcomes (Proximal):

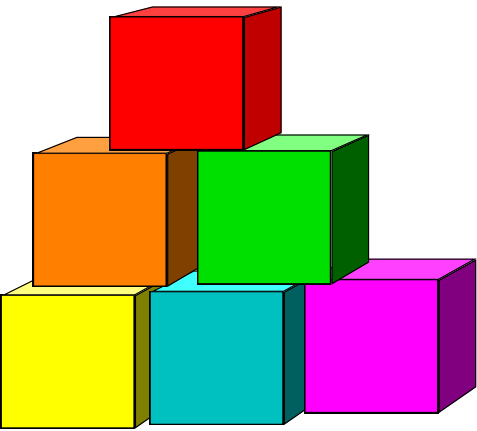
- Increased CG QOL,
- Decreased burden from tasks,
- Decreased distress from symptoms

McMillan et al., 2006

## Patient Outcome (Distal):

- Decreased symptom distress

McMillan & Small, 2007



# Systematic Assessment In Hospice: A Clinical Trial

- **Premise**: If interdisciplinary team members do adequate assessments, symptom management will be better;
- **709 patient/caregiver dyads** accrued to study;
- **Data collected by RN-LCSW teams** at two hospices;



# Systematic Assessment In Hospice: A Clinical Trial

## Results:

- Significant improvement over time in patient depression scores (CES-D);
- Symptom scores improved but not significantly



# Cardiac COPE: Study Results

- **No improvement in any variables:**
  - CG QOL or Burden
  - Patient QOL
  - Patient symptoms

**How could this happen?**



# Saved by Qualitative Data!

## 10 HF caregivers interviewed after COPE

- “Everything they were discussing, we were already doing”.
- “I already knew everything; we needed this at the beginning”.



# Lesson Learned:

Cancer researchers should NOT  
conduct cardiac research!



**Focus!**

# Moving upstream:

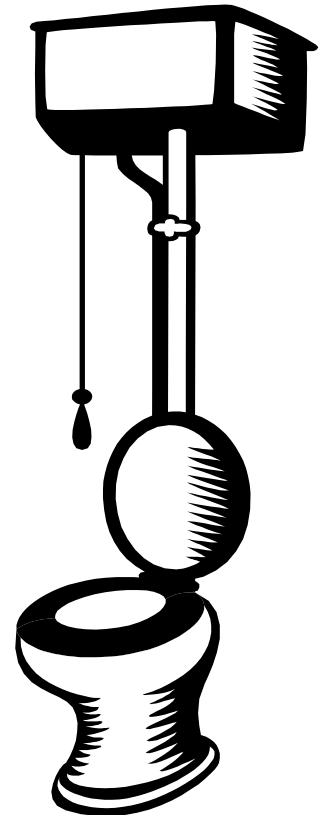
- Qualitative data: COPE is needed sooner, when patients are diagnosed with HF;
- Networking with other investigators led to studies being conducted in other parts of the U.S.



# Medication-Induced Constipation

- **Purpose:** To determine the severity and trajectory of constipation among cancer patients at risk for constipation due to opioids.

**Funded by NINR  
(5R01 NR008270)**





# Methods

**Sample:** 255 outpatients from an NCI- designated comprehensive cancer center;

- With a variety of types of cancers;
- At risk for constipation due to opioids.



# CAS Scores by Week

(Possible Range 0-16)

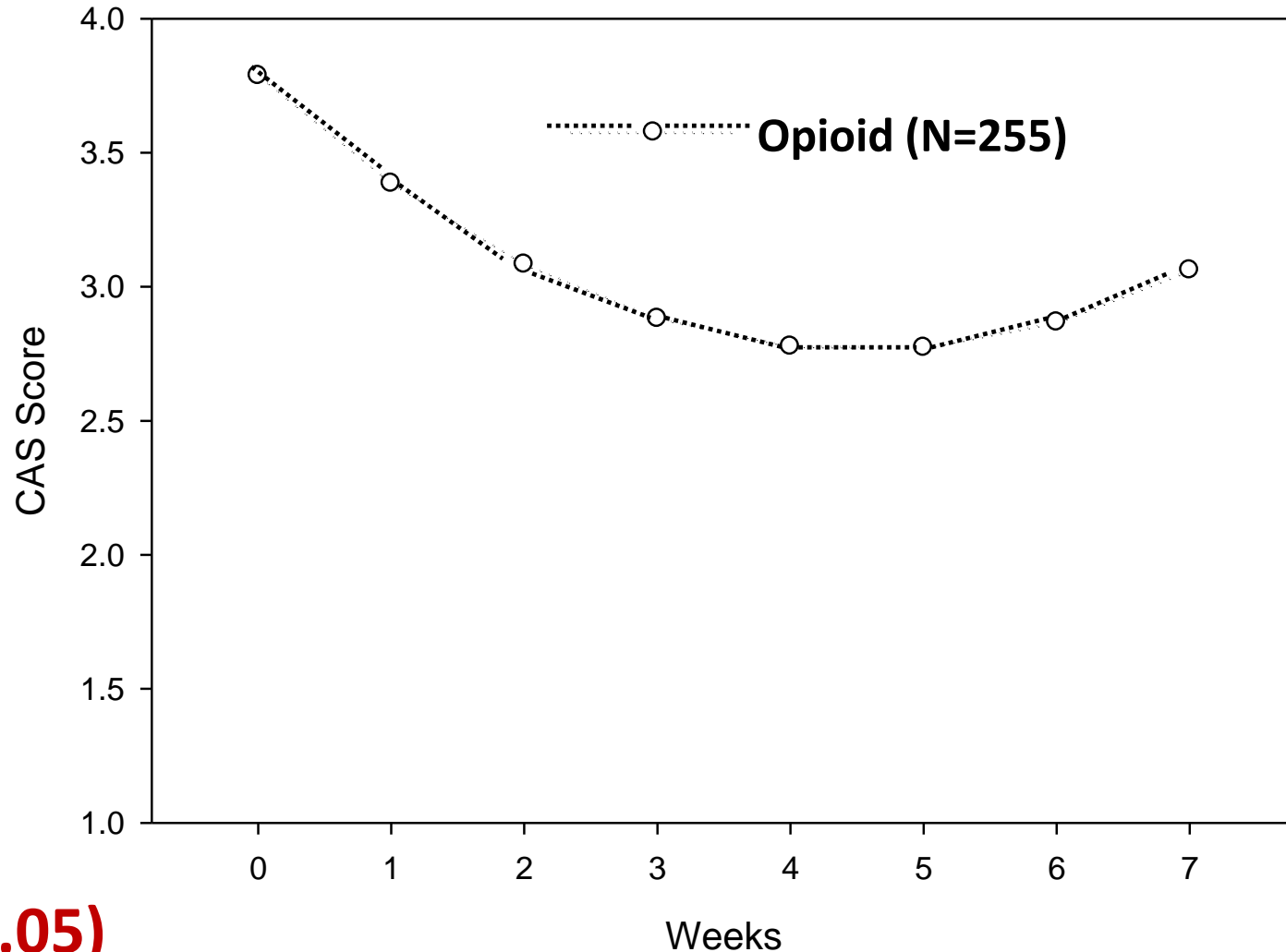


Week	N	Range	Mean	SD
1.	255	0-14	3.8	3.2
2.	216	0-13	3.4	3.1
3.	202	0-16	3.1	3.0
4.	185	0-13	3.0	3.0
5.	175	0-12	2.8	2.7
6.	168	0-14	2.8	2.9
7.	167	0-14	2.7	2.9
8.	161	0-14	3.0	3.1

**63% reported constipation**

**Attrition = 94 (37%)**

# CAS Mean Score Trajectory over 8 weeks\*



\*(P=.05)

**If COPE was needed  
upstream for HF patients,  
why not for cancer  
patients?**



# Upstreaming led to:

- “COPE for cancer patients: a clinical trial”
- Revised COPE manual again for use by cancer patients rather than caregivers;
- Funded 2013-2016.

PCORI 4025



# Patient Self-Management: COPE

- **Results: No significant improvements**
- **We hypothesize that while 3 sessions works for caregivers, it was not enough for patients;**
  - **Patients overwhelmed and distracted**
  - **Chemo-brain likely a problem**



# Most Important Lessons Learned

- Be Persistent
- Be flexible but focused



# Questions?

