



Schulich

MEDICINE & DENTISTRY

Understanding non-malignant inpatient palliative care referral triggers: a qualitative approach

May 15, 2024

Disclosure of Commercial Support

- This program has received no in-kind support.
- This program has financial support from the Palliative Pain and Symptom Management Program, St. Joseph's Health Care London.

Potential for conflict(s) of interest:

Members of the Planning Committee have disclosed the following potential conflicts of interest:

- Jenn Verhoeven: employed by St. Joseph's Health Care London.

Mitigating Potential Bias

Conflict of Interest disclosure forms have been completed by all presenters and reviewed by the Planning Committee to ensure no bias exists.

Today's Objectives

- **Discuss current landscape of non-malignant inpatient palliative care**
- **Introduce and review constructivist grounded theory**
- **Discuss project results and next steps for continued improvement in inpatient referral triggers**

Palliative Care Grand Rounds Series

- **A palliative care approach to end-stage renal disease** - Dr Natan Veinberg
- **Palliative care and the patient with advanced heart failure** - Dr Leah Steinberg
- **Palliative care and critical limb ischemia** - Dr Jordan Berry
- **The changing face of palliative care: moving from end-of-life care to early integration** - Dr Eduardo Bruera

Non-malignant (NM) palliative care: a brief review

NM palliative care review - symptoms

- **Non-cancer patients face symptom burden that is overall similar to cancer patients** (Moens et al, 2014; See et al, 2022)
- **Most common symptoms** (Moens et al, 2014; See et al, 2022):
 - Pain
 - Fatigue
 - Dyspnea
 - Anxiety/Psychological



NM palliative care review - symptoms

- **Non-cancer patients are more likely to be** (Moens et al, 2014):
 - Older age
 - Multi-morbid
 - Frail
 - Lower baseline functional status



NM palliative care review - benefits

- **Non-cancer patients who see palliative care have:**
 - Reduced symptom burden (Quinn et al, 2020)
 - Improved quality of life (Rogers et al, 2017)
 - Less acute healthcare usage (Quinn et al, 2020)
 - Specifically when palliative care is involved early

NM palliative care review - guidelines

- Nearly all specialty groups have consensus guidelines regarding the need/benefit of palliative care involvement in their specific patient group



**Canadian
Cardiovascular
Society**



Ontario Renal Network



CGS · SCG

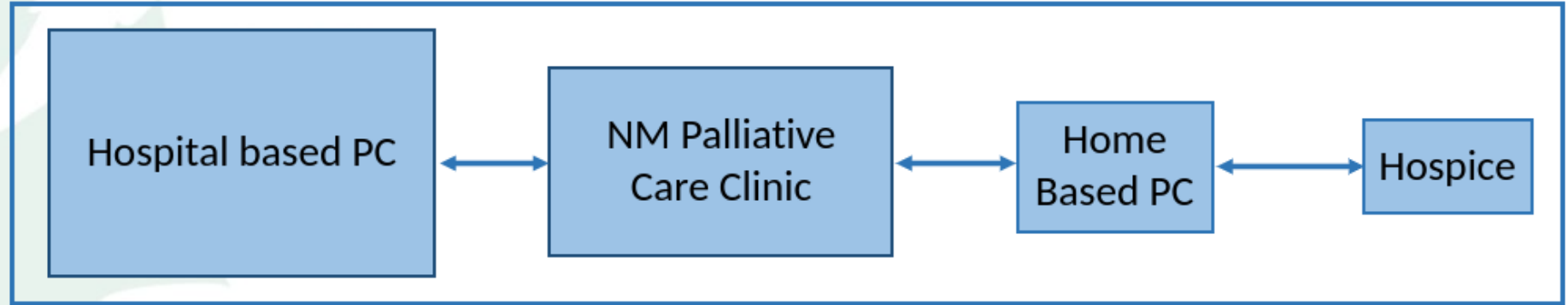
CANADIAN GERIATRICS SOCIETY

LA SOCIÉTÉ CANADIENNE DE GÉRIATRIE

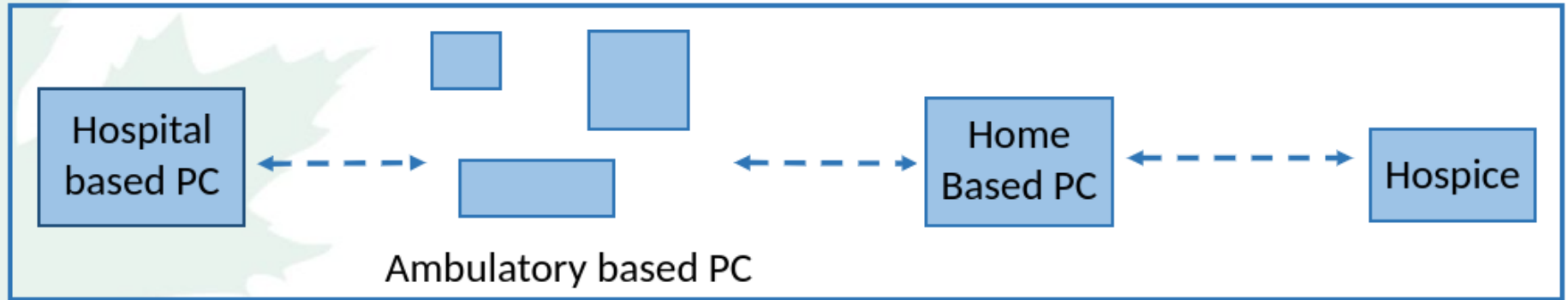
NM palliative care review - role

- **What is the palliative care role in NM patients?**
 - Pain and symptom management
 - Iterative goals of care and advanced care planning discussions
 - Longitudinal psychosocial support

NM palliative care review - role



NM palliative care review - role



NM palliative care review - barriers

- **Misconceptions about palliative care** (Siouta et al, 2018)
 - Palliative care = end of life care
 - Active medical treatment and PC are mutually exclusive
- **Lack of standardized approach** (Beck et al, 2016; Bonares et al, 2021)
 - No clear criteria/standardization on when to refer
 - Many specialists unaware of local PC referral criteria

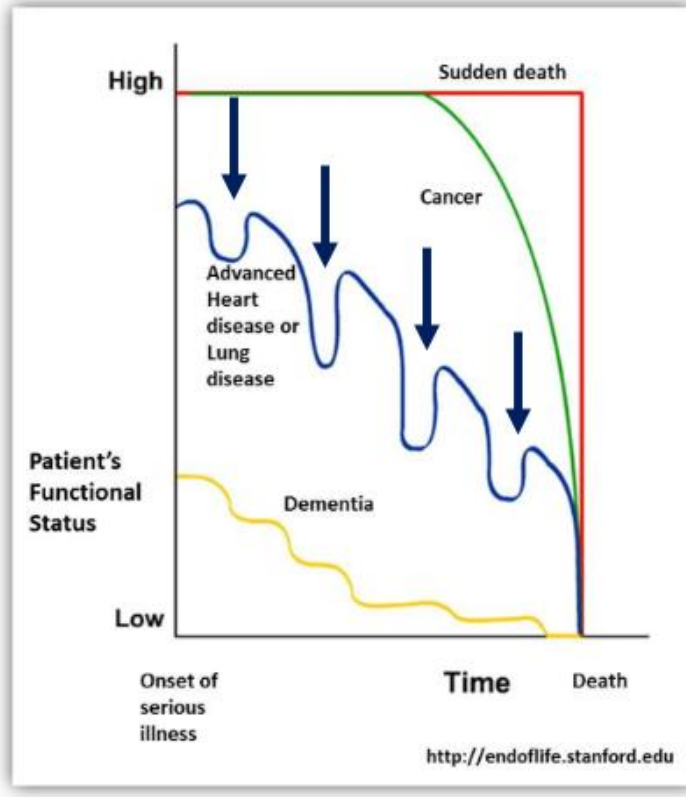
NM palliative care review - barriers

- **Concerns re: impact on patient care** (Ufere et al, 2019)
 - Patients will think treating team has abandoned them
 - Patient will give up hope

NM palliative care review - role

- **Non-malignant palliative care requires a dynamic and fluid approach**
 - Given the uncertain nature of NM illness, role needs to shift and change over time
- This role is determined by a number of factors:
 - Goals of care
 - **Prognosis**
 - Specialist and primary care involvement
 - Patients needs

NM palliative care review - prognosis



NM palliative care review - referral triggers

Sex	Points	ED visits*	Points	Home O ₂	Points	Diagnostic Risk Score
Female	0	0	0	No	0	Same as measured in Appendix 1
Male	1	≥ 1	1	Yes	4	

Admission directly to ICU	Points	Admissions by ambulance*	Points	Urgent 30-d readmission	Points
No	0	0	0	No	0
Yes	2	1	3	Yes	1
		≥ 3	5		

Charlson Comorbidity Index score			
Diagnosis	Points	Diagnosis	Points
Myocardial infarction	1	Diabetes with chronic complications	2
Congestive heart failure	2	Hemi- or paraplegia	1
Peripheral vascular disease	1	Renal disease	3
Cerebrovascular disease	1	Nonmetastatic cancer	2
Dementia	3	Moderate to severe liver disease	4
Chronic respiratory disease	2	Metastatic cancer	6
Mild liver disease	2	HIV infection	4
Diabetes without complications	1	Total comorbidity score	—

Age × comorbidity							
Charlson Comorbidity Index score							
Age, yr	0	1	2	3	4	5	≥ 6
20-24.9	0	3	5	7	8	9	10
25-29.9	2	5	7	9	10	11	11
30-34.9	4	7	9	11	12	13	13
35-39.9	7	9	11	12	13	14	15
40-44.9	8	11	13	14	15	15	16
45-49.9	10	13	14	15	16	17	17
50-54.9	12	14	16	17	17	18	18
55-59.9	14	16	17	18	19	19	20
60-64.9	15	17	18	19	20	20	21
65-69.9	17	19	20	21	21	22	22
70-74.9	18	20	21	22	22	23	23
75-79.9	20	21	22	23	23	24	24
80-84.9	21	23	23	24	24	25	25
85-89.9	23	24	25	25	25	26	26
90-94.9	24	25	26	26	26	27	27
≥ 95	25	26	27	27	27	28	28

Living status / admission urgency × admissions by ambulance				
Living status	No. of admissions by ambulance			
	0	1	2	≥ 3
Home, independent	0	0	0	0
Rehabilitation facility	3	3	2	2
Home with home care	4	3	3	3
Nursing home	4	4	4	3
Chronic care hospital	8	6	5	5
Admission urgency				
Elective	0	0	0	0
ED, no ambulance	3	1	0	0
ED, ambulance	5	2	1	0

Admitting service†	Points
Medicine	
General medicine	10
Cardiology	8
Gastroenterology/nephrology/neurology	9
Palliative care	28
Hematology/oncology	14
Ante/intra/postpartum	0
Gynecology	7
Surgery	
General surgery	8
Cardiovascular surgery	9
Neurosurgery	10
Orthopedic/plastic surgery	7
Thoracic/transplant surgery	7
Trauma	8
Urology	6

Covariate	Total points
Sex	—
ED visits	—
Home O ₂	—
Diagnostic Risk Score	—
Admission to ICU	—
Admissions by ambulance	—
Urgent readmission	—
Admitting service	—
Age × comorbidity	—
Living status/admission urgency × admissions by ambulance	—
Total HOMR score	—

NM palliative triggers

Referral

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Other conditions

Deteriorating with other conditions, multiple conditions and/or complications that are not reversible; best available treatment has a poor outcome.

Review current care and care planning.

- Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family/people close to them. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.



NM
trig

<p>Chronic Obstructive Pulmonary Disease (COPD)</p>	<ol style="list-style-type: none"> 1. Moderately disabled; dependent. Requires considerable assistance and frequent care (Karnofsky-score \leq 50%) 2. Substantial weight loss (\pm10% loss of bodyweight in six months) 3. presence of congestive heart failure 4. Orthopnoea 5. Patient gives signals of approaching end of life 6. Objective signs of serious dyspnoea (decreased dyspnoea d' effort, dyspnoea with speaking, use of respiratory assistant muscles and orthopnoea)
<p>Congestive heart failure (CHF)</p>	<ol style="list-style-type: none"> 1. Severe limitations. Experiences symptoms even while at rest. Mostly bedbound patients.(NYHA IV) 2. Frequent hospital admissions (>3 per year) 3. Frequent acute decompensated heart failure (>3 per jaar) 4. Moderately disabled; dependent. Requires considerable assistance and frequent care (Karnofsky-score \leq 50%) 5. Increase in weight which does not react on raising the amount of diuretics 6. Algehele achteruitgang in clinical situation (oedema, orthopnoe, nycturie, dyspnoea) 7. Patient gives signals of approaching end of life
<p>Oncology</p>	<ol style="list-style-type: none"> 1. Worse prognosis primary tumor 2. Moderately disabled; dependent. Requires considerable assistance and frequent care (Karnofsky-score \leq 50%) 3. Progressively decline in physical functioning 4. Progressively bedridden 5. Diminished voedsel intake 6. Toenemende vermagering 7. Anorexie-cachexie syndrom (afname eetlust, algemene zwakte, vermagering, spieratrofie) 8. Diminished 'drive to live'



NM
trig

Chronic Obstructive Pulm
(COPD)

Congestive heart failure (

Oncology

NECPAL CCOMS-ICO 3.1 2017©

PATIENT: _____ HC: _____
 DATE: ____ / ____ / ____ SERVICE: _____
 RESPONSIBLE(S): _____

Surprise Question (to /among professionals)	Would you be surprised if this patient dies within the next year?		<input type="checkbox"/> Yes <input type="checkbox"/> No (-) (+)
"Demand" or "Need"	- Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort?		<input type="checkbox"/> Yes <input type="checkbox"/> No
	- Need: Identified by healthcare professionals from the team		<input type="checkbox"/> Yes <input type="checkbox"/> No
General Clinical Indicators of Progression: - The last 6 months - Not related with recent/reversible concurrent processes	- Nutritional Decline	• Weight loss > 10%	<input type="checkbox"/> Yes <input type="checkbox"/> No
	- Functional Decline	• Karnofsky or Barthel score > 30% • ADLs >2	<input type="checkbox"/> Yes <input type="checkbox"/> No
	- Cognitive Decline	• Loss ≥ 5 minimal or ≥ 3 Pfeiffer	<input type="checkbox"/> Yes <input type="checkbox"/> No
Severe Dependence	- Karnofsky <50 or Barthel <20	• Clinical data anamnesis	<input type="checkbox"/> Yes <input type="checkbox"/> No
Geriatric Syndromes	- Falls - Pressure Ulcers - Dysphagia - Delirium - Recurrent infections	• Clinical data anamnesis ≥ 2 recurrent or persistent geriatric syndromes	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Persistent symptoms	Pain, weakness, anorexia, dyspnoea, digestive...	• Symptoms Checklist (ESAS) ≥ 2 persistent or refractory symptoms
Psychosocial aspects	Distress and/or Severe adaptive disorder	• Detection of severe emotional distress > 9	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Severe Social Vulnerability	• Social and family assessment	<input type="checkbox"/> Yes <input type="checkbox"/> No
Multi morbidity	>2 advanced chronic diseases or conditions (from the list of specific indicators)		<input type="checkbox"/> Yes <input type="checkbox"/> No
Use of resources	Evaluate Demand/Intensity of interventions	• > 2 urgent or not planned admittances in last 6 months • Increase Demand/Intensity of interventions (homecare, nurse interventions, etc)	<input type="checkbox"/> Yes <input type="checkbox"/> No
Specific indicators of disease severity and progression	Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced	• To be developed as annexes	<input type="checkbox"/> Yes <input type="checkbox"/> No

Classification:		
Surprise Question (PS)	SQ + (I would not be surprised)	✓
	SQ - (I would be surprised)	
NECPAL Parameters	NECPAL + (de 1+ a 13+)	
	NECPAL - (No parameters)	✓

Codification and Registry
 Propose codification as Patient with Advanced Chronic Conditions (PCC)

- Fellowship Project

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Chronic Obstructive
(COPD)

Congestive heart fai

Oncology

Table 1 TW-PCST criteria.

Screening Items	Scoring												
A. Basic disease process 1. Cancer (Metastatic/Recurrent) 2. Advanced COPD 3. End-stage liver disease 4. Kidney dialysis (age ≥ 65 , dialysis for >2 years) 5. Advanced cardiac disease 6. Neurologic disease with severely reduced function (i.e. stroke, coma, dementia resulting in bed-bound) 7. Other life-limiting acute illness (i.e. ARDS, sepsis, MODS)	Score 2 points EACH												
B. Concomitant disease process 1. Cancer (primary) 2. Moderate COPD 3. Liver cirrhosis 4. Kidney dialysis (others) 5. Moderate congestive heart failure 6. Other condition complicating cure	Score 1 point EACH												
C. Functional status of patient Using ECOG Performance Status (Eastern Cooperative Oncology Group)	Score as specified left												
<table border="0"> <tr> <td><i>Score</i></td> <td><i>Scale</i></td> </tr> <tr> <td>0</td> <td>Fully active, able to carry on all pre-disease activities without restriction.</td> </tr> <tr> <td>0</td> <td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work.</td> </tr> <tr> <td>1</td> <td>Ambulatory and capable of all self-care but unable to carry out any work activities.</td> </tr> <tr> <td>2</td> <td>Capable of only limited self-care; confined to bed or chair</td> </tr> <tr> <td>3</td> <td>Completely disabled. Cannot carry on any self-care.</td> </tr> </table>	<i>Score</i>	<i>Scale</i>	0	Fully active, able to carry on all pre-disease activities without restriction.	0	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work.	1	Ambulatory and capable of all self-care but unable to carry out any work activities.	2	Capable of only limited self-care; confined to bed or chair	3	Completely disabled. Cannot carry on any self-care.	
<i>Score</i>	<i>Scale</i>												
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1	Ambulatory and capable of all self-care but unable to carry out any work activities.												
2	Capable of only limited self-care; confined to bed or chair												
3	Completely disabled. Cannot carry on any self-care.												
D. Other criteria to consider in screening The patient: <ol style="list-style-type: none"> 1. Team/patient/family needs help with complex decision-making and determination of goals care 2. has unacceptable level of pain 3. has uncontrolled psychosocial or spiritual issues 4. has frequent visits to the Emergency Department (>1 x mo for same diagnosis) 5. has more than one hospital admission for the same diagnosis in last 30 days 6. has prolonged stay in ICU(s) without evidence of progress 7. is in an ICU setting with documented poor or futile prognosis 8. has prolonged length of stay (>30 days) without evidence of progress 	Score 1 point EACH												
Total Score: A + B + C + D =													

les and orthpnoea)

NYHA IV)

Research questions

- What are the barriers to PC referrals for non-malignant patients at University Hospital?
- Are PC referrals being placed at the “right” time?

An introduction to Constructivist Grounded Theory (CGT)

CGT Origins

- Research method developed in the 1960's by Sociologists Barney Glaser and Anselm Strauss
- Initial research observed how dying occurred in a variety of hospital settings
 - How physicians determined terminal illness
 - How this was communicated
 - How patients handled the news
- More recently has been used in educational and nursing research

What is CGT?

- “Stated simply, grounded theory methods consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories ‘grounded’ in the data themselves” (Charmaz, 2006)
- Approach differed from previous “armchair logico-deductive theorizing”

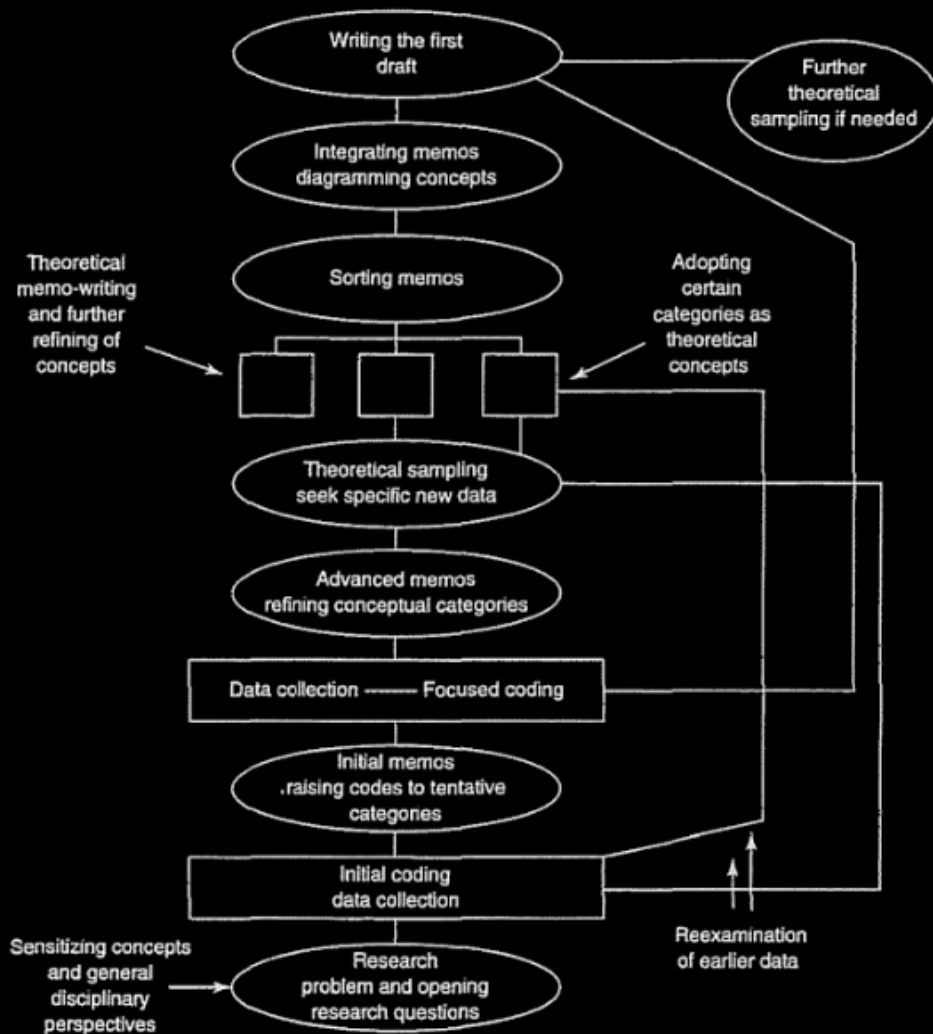


What is CGT?

- Simultaneous involvement of data collection and analysis
- Constructing codes and categories from data as opposed to preconceived deduced hypotheses
- Uses a constant comparative analysis
- Sampling aimed toward theory construction

What is

- Fellowship Project



What is “rich” data?

- Obtaining rich data means seeking “thick” description (Geertz, 1973)
- This can be obtained from:
 - Field notes and observations
 - Written interview accounts
 - **Compiling detailed narratives**

What is “rich” data?

- Obtaining rich data means seeking “thick” description (Geertz, 1973)
- This can be obtained from:
 - Field notes and observations
 - Written interview accounts
 - **Compiling detailed narratives**
- KEY TO CGT
 - Theories are not forced on data, data leads you to the theories

The data - a “rich narrative”

- Once a chart was chosen, a rich narrative was developed
- A written account of the patient’s admissions to hospital within the past year
- Includes a chart review of all medicine, palliative care team and consultant notes throughout each admission in hospital

The data - a “rich narrative”

Admitted to hospital from retirement home with diagnosis of delirium. History of atrial fibrillation, hypertension, coronary artery disease, prior cancer x 2 (prostate and renal, both excised), with a possible underlying malignancy NYD (lymphadenopathy and PE). On admission, was DNR-restricted. Found to have severe HFrEF, thought to be related to viral myocarditis. No reversible cause for delirium was identified, and in light of new HFrEF diagnosis, the MRP team discussed transitioning to comfort care based on previously expressed values of not wanting to pursue medical treatment if cognitively incapacitated. Palliative care was consulted 8 days after admission and it was deemed that he would not be a candidate for transfer to palliative services given that they were not prepared to transition to comfort care. There was some confusion around treatment at the end of life vs a comfort care approach, likely because the prognosis related to the new heart failure diagnosis was uncertain, as heart failure treatment hadn't been initiated. There was a lot of communication between palliative care team and the patient, as well as palliative care team and MRP team to clarify and to request updates for clarification to the patient. Ultimately, they decided to continue treatment with diuresis and the patient's PPS ended up improving throughout hospitalization, although cognitive function never returned to baseline. In the end, it was decided to discharge this patient to LTC and not to pursue a comfort care approach. Subsequently he presented to the ED with a fall but did not require admission. No follow up with palliative care was provided.

The data - a “rich narrative”

The patient was admitted to hospital with acute on chronic diarrhea following multiple courses of antibiotics for a parotid gland infection in the context of Sjogren’s Disease. Additional key diagnoses from the patient’s past medical history include systemic sclerosis complicated by esophageal dysmotility, peptic strictures, and severe reflux esophagitis.

The patient presented to hospital with acute on chronic diarrhea associated with significant weight loss in the context of recent antibiotic use as above. No specific cause for her diarrhea was determined on infectious work-up. Her stay in hospital was complicated by query melena with hemoglobin drop and recurrent parotid gland infection. During her stay, she was seen by allied health who noted ongoing weight loss secondary to impaired oral intake, as well as frailty and functional decline. Complications of her esophageal dysmotility and severe mouth pain noted during admission included anorexia/cachexia and hypovolemic hyponatremia.

Palliative Care was consulted early in the patient’s stay for an opinion regarding her mouth pain, as well as to assist with goals of care and disposition planning considering her worsening functional status with lack of reversible cause (given patient was not interested in tube feeding). At the time of admission and palliative care consultation her code status was DNAR-Restricted. The patient’s PPS at the time of palliative care consultation was PPS 40%. She was seen by palliative care eight times prior to discharge.

The patient was discharged home from hospital with PCOT supports but represents about two months later with falls and a functional decline. Notes indicate that her presentation to hospital was in part triggered by her daughter contracting COVID and being unable to support her in the home. This resulted in a decrease in oral intake.

In hospital she was noted to have significant peripheral edema, a new pleural effusion, a new pericardial effusion, ascites and severe hypertension. Her MRP team felt her presentation was concerning for scleroderma renal crisis. Ultimately the patient is treated medically and stabilizes. A family meeting is held without our team approximately 1.5 weeks after her admission. As a result of that meeting, her code status is transitioned a comfort focused plan of care by her MRP with the consent of her daughter (as the MRP deems her inability to understand the differences between MAID and comfort-focused care as an indication that she doesn't have capacity for the decision). However, the MRP then has a discussion with the patient directly after her family meeting and consent is obtained for smaller decisions in her care (stopping blood work, stopping certain medications). The patient is monitored clinically by our team to determine best palliative disposition plan; hospice application submitted. Patient is transitioned to SAMU while awaiting palliative placement. Ultimately, Hospice rejects application. Parkwood PCU application placed. While waiting, patient starts to decline clinically (agitation/restlessness, new O2 needs concerning for aspiration). Two days before her death she had a witnessed generalized tonic-clonic seizure in the context of hypoxia secondary to aspiration. Ultimately she died quite rapidly while on SAMU.

Palliative Care was consulted within the first 24 hours of admission to revisit goals of care. Her code status at the time of admission was DNAR-Restricted. Her code status after Palliative Care referral was unchanged as she was unable to come to any clear decision regarding her goals of care at that time given conflicts between her desire to focus on comfort in light of severely impaired quality of life and her religion. Her PPS at the time of consultation was noted to be 30%. She was assessed 31 times by the Palliative Care team prior to death in hospital.



Intentional/deliberate sampling

- Samples selected by the investigating team on the basis of the purpose, with the intention of forming a true representation of the data



Intentional Sampling

- Broken down into 4 main components with that were then further characterized
 - Admission/discharge patterns
 - Single admission
 - Multiple admissions in last 12 months
 - Discharge to home/LTC/PCU/Hospice
 - Discharge with or without palliative follow up
 - Type of palliative follow up (outpatient VS PCOT)
 - Death in hospital
 - Diagnosis
 - Acute life limiting
 - Chronic progressive

Intentional Sampling

- Broken down into 4 main components with that were then further characterized
 - Palliative Care consult pattern
 - One and done
 - Intermittent follow ups
 - Consistent longitudinal follow ups
 - Timing of Palliative Consult
 - On admission
 - Middle of admission
 - Close to discharge/death

Coding data

- Categorizing segments of data with a short name that summarizes and accounts for each piece of data
- Allows you to separate and sort data to sharpen analytic accounting of data
- “Coding is the pivotal link between collecting data and developing an emergent theory to explain these data”

Coding data - examples

- “MRP team recognizing futility of medical treatments, but patient focused on active treatment and not engaging in bigger picture conversations”
- “Prognostic uncertainty stopping team from referring to palliative care, but recognizing a continued clinical decline in the patient”
- “The patient is requesting a comfort focus for their care but their acute medical illness has been reversed”
- “The patient has a high degree of symptom burden that is not improving with management of their acute illness”
- “The patient is on a CADD pump in the community”

Coding data - examples

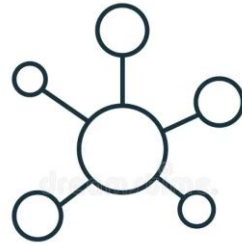
- “The patient is on opioids for chronic pain and the medicine team is looking for help on management”
- “The team is struggling to communicate prognostic uncertainty”
- “Team is uncomfortable with the patients current code status”
- “The team recognizes a patient at risk for recurrent readmission in a patient with a chronic illness, but not a terminal illness, and are looking for support in longitudinal follow up”

Memo writing

- Once an initial pass on coding the narratives is completed, our team reviewed the data and compared our thoughts
- Allows multiple points of view to be integrated into the data
- Goal is to reach a stage where no new codes are developing on review of the narrative
- ***Pivotal step between data collection and drafting theories

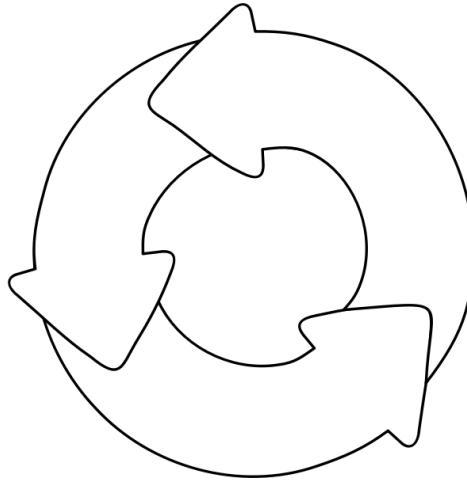
Clustering/grouping

- Analyzing codes to create clusters or “rational subgroups”



CLUSTERING

Theoretical Sampling



Theoretical sampling

- Seeking further pertinent data to develop the emerging theory
- Allows you to elaborate and refine the codes or rational subgroups that you have already started creating
- The goal of theoretical sampling is to continue to develop new properties of your categories/codes and it continues until no further properties are emerging

Theoretical sampling - Saturation

- Categories are “saturated” when further data collection no longer sparks new theoretical insights
- No further properties of your core theoretical categories are being revealed

Saturation

- ****Tricky to know when you have saturated****



Fellowship Project

Referral

Pain and symptom management

End of life symptom
management

Chronic symptom
management

Emerging Barriers

End of life symptom
management

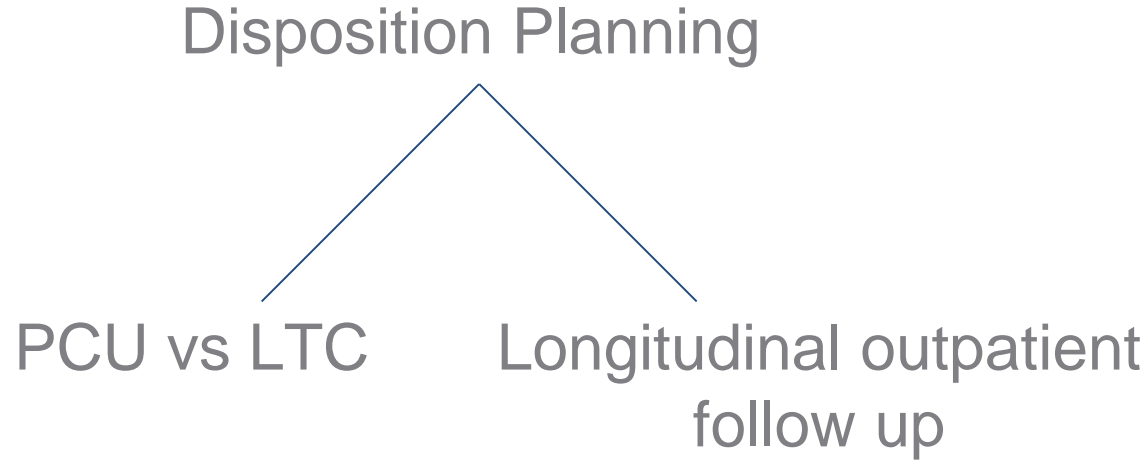
No barriers

Chronic symptom
management

Patient/family refusal

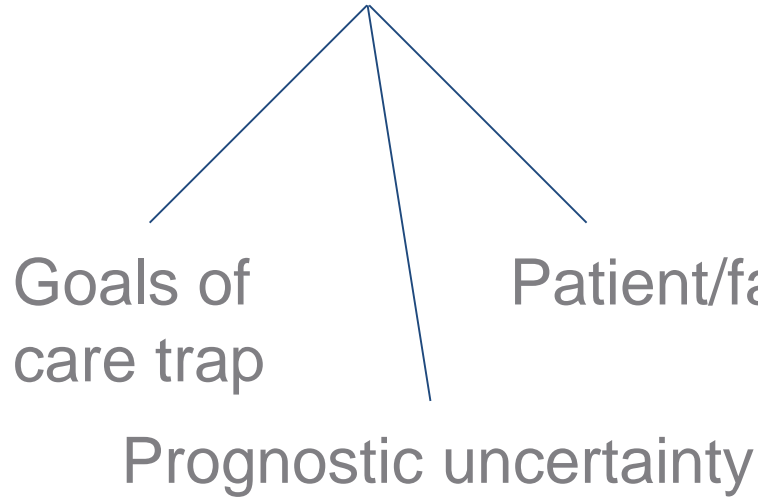
Uncertain eligibility

Referral

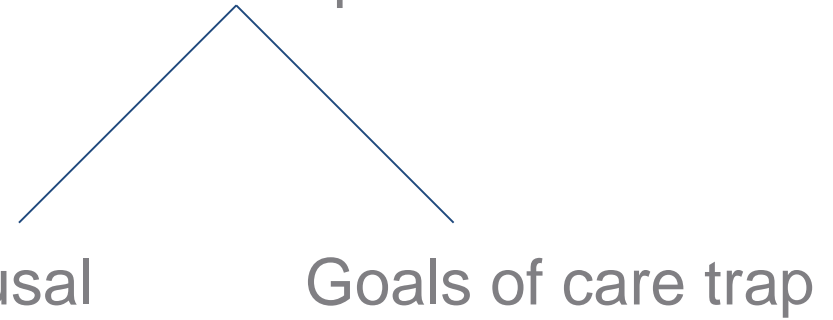


Emerging Barriers

PCU vs LTC



Longitudinal outpatient follow up



Referral

Goals of Care

Prognostic confidence with patient/family not understanding

Lack of prognostic confidence but clinical course not improving

Conflict between patient and family

Emerging Barriers

Prognostic confidence but patient's goals not aligned

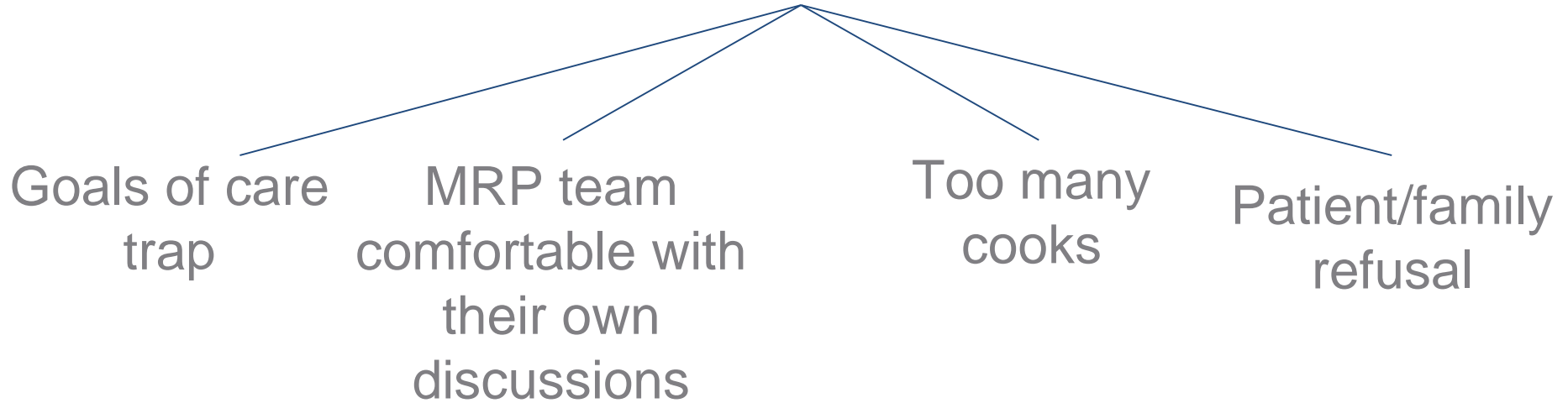
Goals of care trap

MRP team
comfortable with
their own
discussions

Patient/family
refusal

Emerging Barriers

Lack of prognostic confidence but clinical course not improving



Emerging Barriers

Conflict between patient and family



Patient/family
refusal

Referral

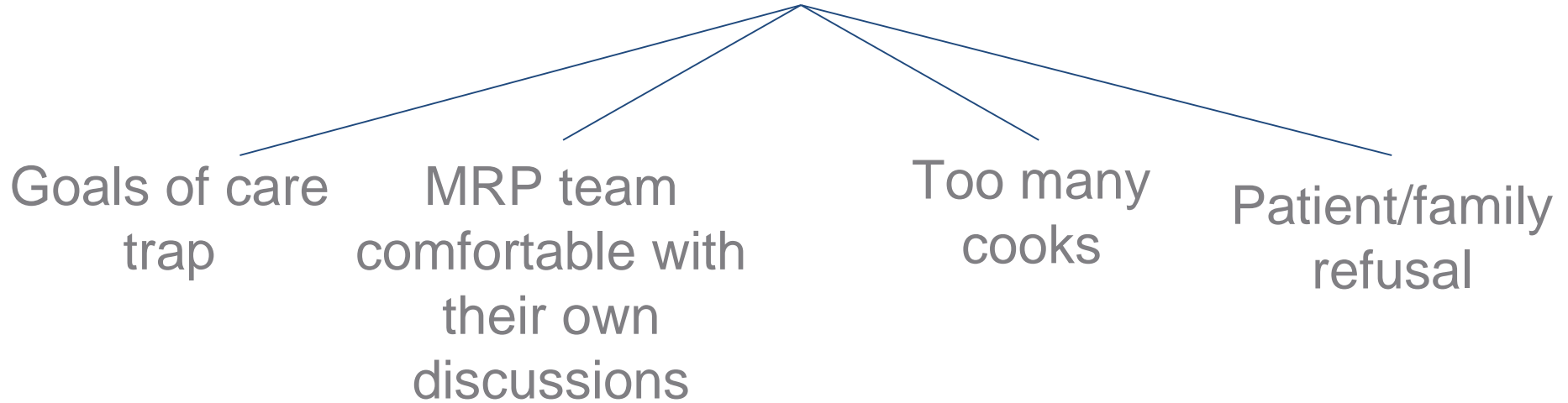
End of life care



End of life care

Emerging Barriers

End of life care



Next Steps

- Further theoretical sampling and production of rich narratives
- Development of new codes and thus new groupings for referral patterns and barriers
- Saturating our data set
- Ultimately, quality improvement projects targeted at specific barriers identified through our work

Limitations

- Specific to our center
- Incomplete documentation
 - Copy and paste world
- Will we ever saturate?

Summary

Summary

- Non-malignant palliative care is on the rise and early palliative care involvement is showing proven benefit
- There remains a lack of timely referrals in this patient population
- Constructivist Grounded Theory is a qualitative method that adds rigor to the traditional qualitative approach and allows a rich description of data to lead our theories
- Through this, subgroups are beginning to be identified for barriers to early palliative care involvement at University Hospital
- Ultimately, the aim will be QI projects targeted at these subgroups for improving referral timing for this patient population



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