

PATH:

A new model for end of life care
in frail older adults

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Outline

- Challenges to optimal care for frail older adults
- PATH: Vision and Principles
- PATH in action
 - Dementia: the X factor for prognosis
 - Clinical settings
 - Guidelines and Training
- Future directions





Why PATH, Why now?

- Population aging
- Byproduct of medical advances/technology = unprecedented levels of co-morbidities (frailty)
- Unprecedented frequency of poor functional outcomes¹
 - Are current models of care missing the mark?
- A new model of care is needed

[1. Gerontology.](#) 2009;55(3):269-74. Epub 2009 Jan 12.



History Repeating

“It seems inevitable that a backlash to such blind optimism would arise... the belief in the cult of cure was so strong that it denied the very existence of dying patients as a class of people. Deaths, if they occurred, were aberrations; in the cult of cure people did not die, they coded. A new social institution was needed. This institution became known as hospice.”

Hallenbeck JL. Perspectives of Palliative Care



EOL care in frailty: echoes from the past

Pre-palliative era	Current EOL care for older adults
<ul style="list-style-type: none">• Withholding information about diagnosis	<ul style="list-style-type: none">• Avoid discussions of prognosis
<ul style="list-style-type: none">• Lack of awareness about palliative care in cancer	<ul style="list-style-type: none">• Lack of awareness of “frailty”• Lack of recognition of dying• Inattention to <i>how</i> people die
<ul style="list-style-type: none">• Comfort care withheld	<ul style="list-style-type: none">• Comfort care delayed
<ul style="list-style-type: none">• Culture of cure	<ul style="list-style-type: none">• Futile treatments offered• Specialty-based mandates
<ul style="list-style-type: none">• Spiritual approach at odds with medical care	<ul style="list-style-type: none">• Insensitivity to needs of dying

With frailty, we have a long way to go

- Recognizing the meaning of frailty
- Choosing interventional treatments

Culture of cure may be harmful

- ▶ Abdominal aneurysm repair for those aged 80 to 84:
 - 7% died
 - 32% were not discharged home
 - 9% had an MI
- ▶ Annual rate of AAA rupture in patients refusing or unfit for surgical repair

5.5 to 5.9 cm	9.4
6.0 to 6.9 cm	10.2
≥ 7.0 cm	37.5

Why are we missing the mark?

- We are poor at predicting *functional* outcomes
- Operative risk scores undervalue frailty
- The importance of baseline function is recognized but...
 - Mortality is not the only important outcome
 - [J Gerontol A Biol Sci Med Sci](#). 2005 Sep;60(9):1180-3.
 - [Gerontology](#). 2006;52(2):92-8.
 - [J Am Geriatr Soc](#). 2008 Jan;56(1):68-75. Epub 2007 Nov 20.

The culture of cure in dementia

- Nursing home residents with advanced dementia or cancer
- Only 1% of dementia cohort perceived as having life expectancy < 6 months
- 6 months after admission to nursing home
 - 92% died with cancer
 - 71% died with advanced dementia
- More aggressive care chosen for dementia cohort

Patients with multi-system disease are often unaware of their health status

90 individuals who were likely to die over the next year according to their doctor

Patient aware of own life expectancy		
	Cancer, %	Heart disease, %
Yes	71	19
No	6	56
Unsure	24	25

Palliative Care Model for Decision Making

- Begin with establishing the patient goals
 - Open ended questions: “What is your greatest fear?”
- Use goals to construct advance directives
- Is this approach best suited for the frail elderly?
 - Multiple interacting co-morbidities
 - Cognition not assessed (MCI)
 - SDM may be placed in a difficult position

Suggested questions may be lost in translation...

- What makes life worth living for you?
- What are your most important hopes?
- What are your biggest fears?
- What would you consider to be a fate worse than death?

Cracks in the Ask-Tell-Ask Model

- Autonomy vs paternalism
 - Does this approach limit autonomy/informed consent?
 - Is tailored disclosure paternalistic?
- How do we apply the model in cognitive impairment?
- The approach provides little guidance about how to provide information or recommendation
 - 93% of people polled want information
 - 92% of people want CPR recommendation

Apatira L et al. Annals IM 2008. 149 (12): 861

White DB. Am J Respir Crit Care Med. Vol 180; 120 -135, 2009



Problem	Solution
Inaccurate history	Collateral informants to obtain history
Narrow focus of assessment	Comprehensive assessment of the older adult
Assessment redundancy	Team based assessment using a shared language and common assessment tool
Missing the story	Standard documentation with information at a glance
Care planning without consideration of frailty	<ul style="list-style-type: none">• Reliance on the whole picture• Increased education to expand scope, while protecting specialization



The PATH model

- Created by two geriatricians and an anthropologist
- Outpatient (clinic and home) and inpatient encounters
 - Care planning at times of crisis or critical decisions for frail older adults
- Physician led: team driven
- Vision: Every frail older adult is empowered to experience optimal quality of life and quality of death by receiving appropriate and compassionate care that matches their unique health status and beliefs



The Principles of Palliative and Therapeutic Harmonization

1 Information changes medical decision making

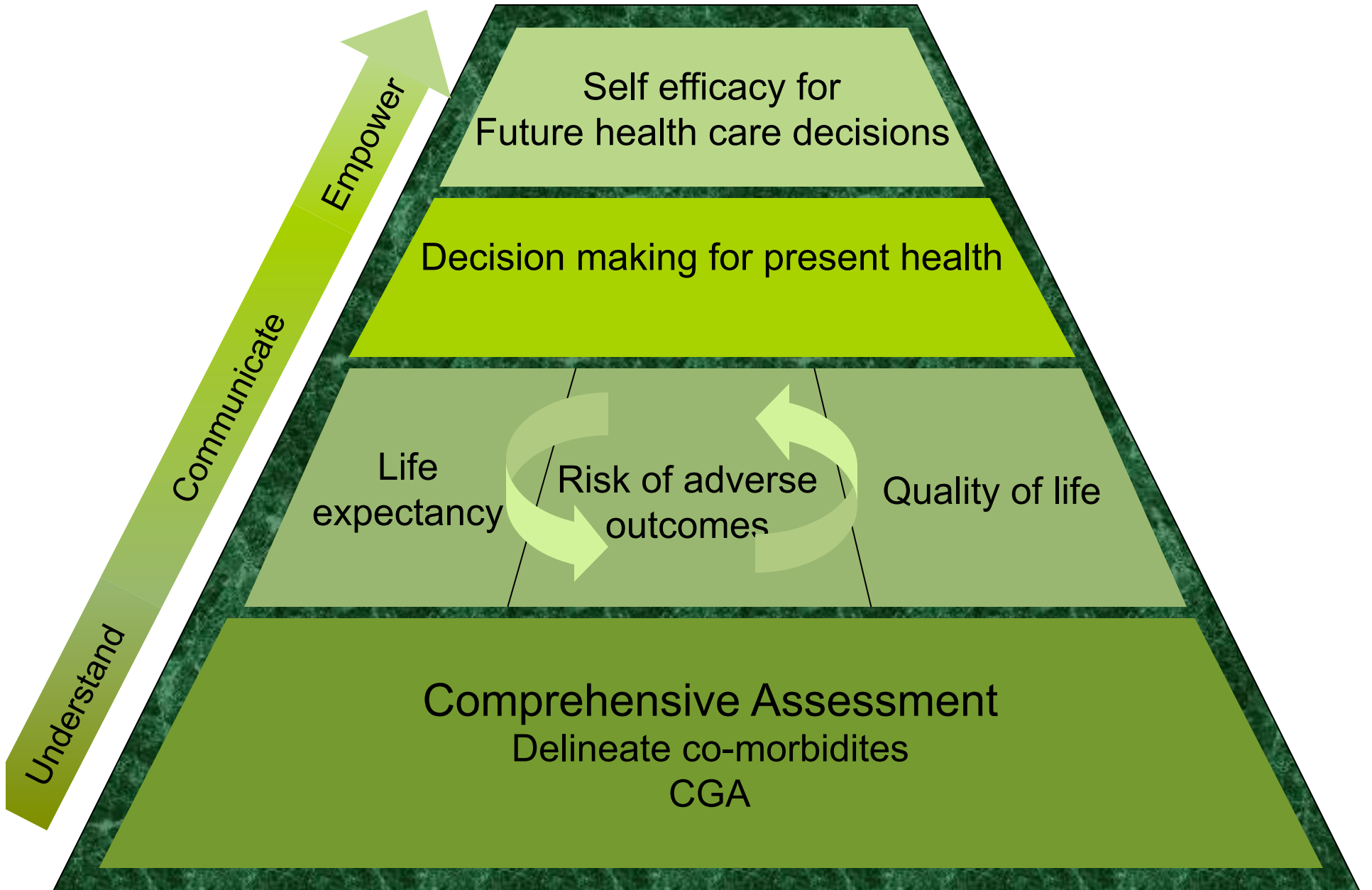
2 Frailty must be at the forefront

3 The outcomes most relevant to the patient should dictate the risk-benefit trade-off

4 It all comes down to asking the right questions

The Principles in Action:

Encounter 1	Understand health status
Encounter 2	Communicate Provide detailed information to patients or their family
Encounter 3	Empower the patient/family to make informed decisions beyond the clinic



Encounter 1

Learn “the story”

Comprehensive Geriatric Assessment

- Cognition (stage)
- Mobility
- Function
- Nutrition
- Social situation
- Medical illnesses
- Medications
- Trajectory



Dementia: the X factor

- Dementia is common and incurable
- Dementia is under-recognized¹
- Dementia predicts adverse outcomes²
 - Many patients never fully recover from delirium³
 - Delirium begets worsening dementia, death, LTC⁴
- Interventions can worsen quality of life⁵⁻⁷
- Dementia changes the how/who of decision making and care planning

1. Patterson CMAJ. 1999;160:S1-15.
2. Fukuse. Chest 2005
3. Bickel. Dementia and Geriatric Cognitive Disorders 2008
4. Fong, RF. Neurology 2009
5. Hanson, L. *JAGS* 2008;56(1), 91-98.
6. Teno, J.M., *JAMA* 2001;285:2081
7. Ferrell, B.A. *Ann Intern Med* 1995;123:681-687



The frailty factor

- It explains the difference between a “good” 85 year old, and a “bad” 85 year old
- It predicts outcomes that matter to patients
 - It helps with treatment planning

Encounter 2

- Focus on sharing information:
- Script ensures knowledge translation
 - Each illness and its expected trajectory described (usually with family member)
 - Dementia and its stages described
 - Frailty
- Acknowledge risk of death:
 - “Your husband is in the final stage of life”

Empower

- Lymphoma patient in NYC:
 - ICU physician asked his mother, “Do you want us to resuscitate your son?”
- Questions:
 - Is there reversible or treatable disease?
 - Would he be able to leave the ICU?
 - What is his expected function and life expectancy following intubation?
 - Is he dying and, if so, will he die comfortably and have the highest quality death in the ICU?
 - How would resuscitation help?
- ICU physician could not answer all these questions, therefore, contacted hematologist

Encounter 3:

Framework for Decision Making

Which health conditions are easily treatable? Which are not?

How will frailty make treatment risky?

How can symptoms be safely and effectively managed?

Will the proposed treatment improve or worsen function or memory?

Will the proposed treatment require time in hospital? If so, for how long?

Will the treatment allow more good quality years, especially at home?

What can we do to promote comfort and dignity in the time left?

Case Example: Pre-PATH

83 year old man

- Moderate stage Alzheimer's dementia
- Congestive heart failure
- Chronic kidney disease: Cr 169 (CrCl = 28)
- Solitary pulmonary nodule: NSCLC
- Living at home, reasonably good quality of life

Case Example

- Resection
 - Significant permanent deterioration in cognition
 - Severe persistent behavioural problems treated with neuroleptic medication
- Could not return home, required NH placement
- Could this outcome have been anticipated and communicated?

Framework for Decision Making

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Case Example

- Consider Life Expectancy:
 - 2000 patients with medically unresectable NSCLC from 26 nonrandomized studies
 - The overall survival at 2 years was 22 to 72%

Rowell. Thorax 2001

Rowell. Cochrane Database 2001



Case 1: Information changes approach

Surgery	BEFORE	AFTER
YES	27%	3%
NO	73%	97%

Medicine	BEFORE	AFTER
YES	22%	16%
NO	78%	84%



The PATH Clinic

- Knowledge translation materials for families
 - Decision Making tools
 - Frailty and its effect on decision-making
 - Dementia Narrative
 - Guides for death at home or hospital
- Wallet cards with Framework questions
- Fighting for a good death: a film that describes the journey of 4 PATH families
- Qualitative analysis of patient/caregiver satisfaction pending



PATH: Experience in Community

- Tertiary care clinic
- Inpatient consultation, and pre-op consultation
- Rural community clinic
 - South Shore Health Team
- Long term care
 - RK MacDonald Nursing Home
- Hospital-based teams
 - Central East LHIN, Ontario



PATH: Preliminary Results

Medical Decisions for the first 100 PATH patients	N, (%)
General	
Care provided at home vs. hospital*	14, (14%)
Comfort care (no further tests or procedures)	53, (53%)
Cancelled pre-arranged specialist appointment e.g. vascular surgery, hematology, internal medicine	39, (39%)
Patients Admitted to Hospital for Cardiac Procedures	28
Declined CABG, catheterization and/or PCI	23, (82% of cardiac patients)
Proceeded with CABG	5, (18% of cardiac patients)
Surgery/Procedures/Tests	
Cancelled pre-arranged surgery, e.g. colectomy, NSCLC resection, nephrectomy, gynecologic, cardiac	27, (27%)
Cancelled procedures e.g. thoracentesis, endoscopy, chemotherapy, radiation therapy, serial cytосcopy	16, (16%)
Dialysis	
Started	1
Avoided/cancelled	8
Cancelled tests (excluding blood work and other simple tests) e.g. MIBI, serial chest CT, echocardiogram, bronchoscopy, serial abdominal US)	5, (5%)
Medications	
Average number of medications stopped per patient	1.65
Average number of medications started per patient	0.36
New decision	93, (93%)



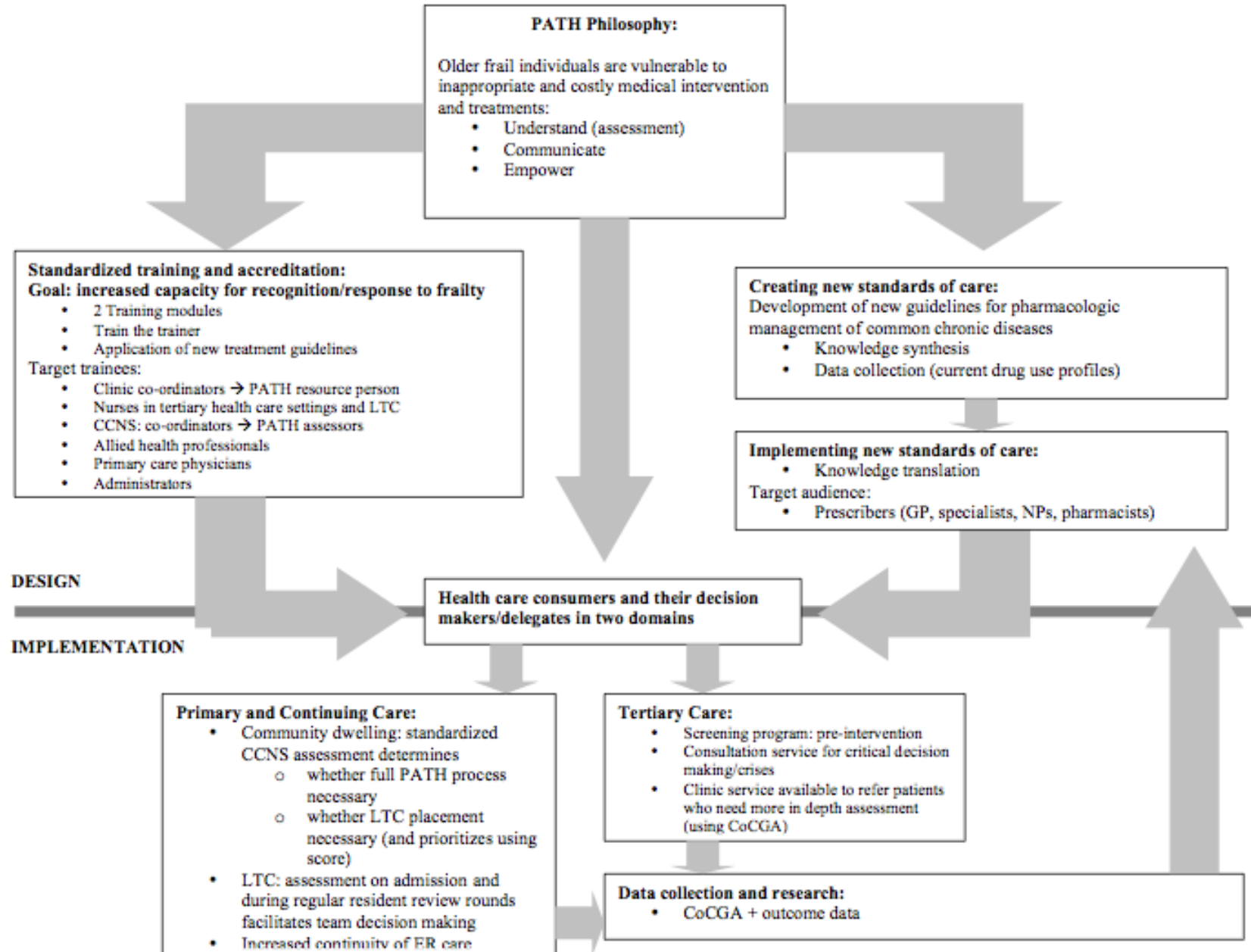
PATH: Training

- 2 Modules
 - Assessment
 - Communication and Empowerment
- Designed for frontline care staff
- Focus on collaborative assessment strategy
- Organization change component
- Train the trainer programming underway

PATH: Guidelines

- Study of most commonly prescribed medications in LTC
 - Over 40% of residents on at least 10 meds at once
 - 75% are on at least 5 medications
 - ? Are these medications helping or hindering
- Knowledge synthesis of clinical practice guidelines and RCT evidence
 - Collaboration with Drug Evaluation Nova Scotia (DEANS) to create academic detailing for GPs

Transforming Health Care for Frail Older Adults Through Palliative and Therapeutic Harmonization (PATH)



Conclusion

- Frailty informs outcomes
- Appropriateness is the new sustainability
- When making care plans, information before values
- PATH provides systematic approach to matching care with care needs
- The process is expandable

Acknowledgements

- Capital Health Innovation Fund
- CDKTN
- Nova Scotia Health Research Foundation

Additional Information

- www.pathclinic.ca
- Fighting for a Good Death (GeGe Productions)

