

# EOL Research Opportunities in New Brunswick



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Extra Mural Program

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# A quick recap:

## New Brunswick Extra Mural Program



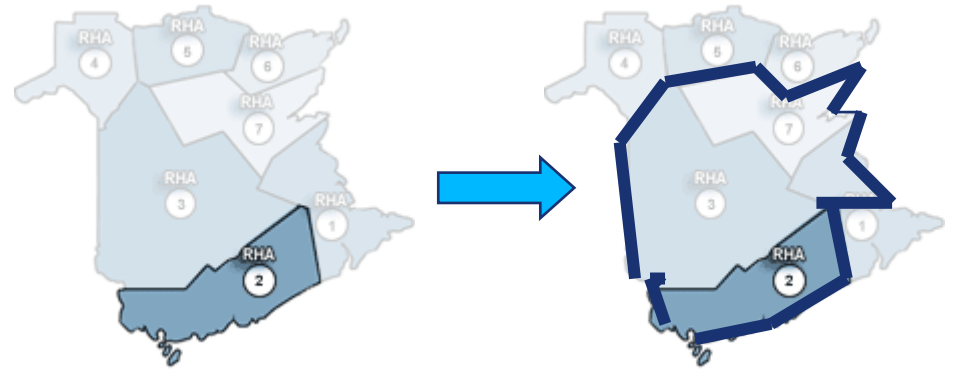
- provincial
- community-based
- multi-disciplinary (RRT, RN, SW, RD, SLP, OT, PT)
- serves patients/families of all ages

Around since the 80s - mission is to promote, maintain, restore optimal levels of health

Case management model

Strong palliative care service (outreach MD)

# The New Brunswick Extra Mural Program



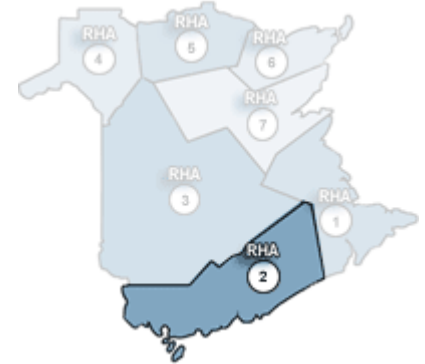
30 delivery sites provide the province with 24 hours, 7day per week service, 365 days per year

5 service delivery units within the current RHA 2

6.5 RRT positions each carrying caseload  $\approx$  80 patients  
(most with COPD and all vulnerable to some extent)

In September 2008, NB moving from 8 RHAs to 2 → increased number RRTs per RHA → increased potential research participants

# So many unanswered questions...

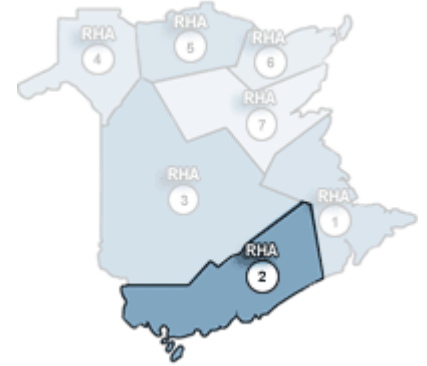


Are these patients hospitalized less often and/or die at home more often than similar patients in other maritime provinces?

Where do patients go after discharge? (They are not all referred to NBEMP, this good/bad?)

Are symptoms under better control? Physical? Psychosocial?

# But we're trying to answer some...



## ***Understanding the Experience of Informal Caregiving In Advanced (COPD): a Qualitative Study***

- funded by NB Medical Research Fund (2008)

Objectives: increase our understanding of the experience of informal caregivers of caring for patients living with advanced COPD (as per CTS guidelines) in a rural setting and to identify potential interventions to enhance these experiences.



## Caregiver Experience (con't)...

Target: 10-20 caregivers in NB (attached to NBEMP). Parallel study in NS to examine differences in Caregivers' Experiences.

To date: 9 caregivers interviewed in NB (currently being transcribed, team to meet re: themes/coding.

Need more male caregivers (end-June 2008)

# The caregivers' story so far...

Fear

Guilt

Abandonment

Need for Respite

Resentment

Spirituality

Duty

Grieving

“Yeah but I had no support. Like the kids would say...Oh, Dad's been going to die for years ... he's going to outlive you and everyone else.”

“Somewhere in all of this, I've lost who I am. I don't know who I am. I don't know if anybody can understand that.”

## More quotes...

I: “When you think about yourself and how you feel about yourself, your self esteem, do you think that’s taken a hit?”

R: “Oh a big hit. Oh, I just feel worthless, really.”

I: “You spend time crying?”

R: “That and praying. I said God has gone on Sabbatical where I’m concerned.”



“And its just every week, there’s less he can do and there’s days that he can do absolutely **nothing** for himself.”

“If I didn’t have the experience with the Lord that I have, the depression would be terrible.

“I am living with a totally different man. So I mean its totally different and I mean, to be honest, I don’t have the feelings for this man.”

“And so my youngest girl is having a real hard time with the fact that her father is being buried with [ex wife]”

“The family is all going to hell”

# CANHELP validation study

- Questionnaire to Measure Satisfaction with EOL Care in Canada
- Nat'l multi-centre study; funded by CARENET
- NBEMP only community-based site.

Objectives: -validation of this questionnaire (communication tool)  
in different settings  
-measuring patient/family satisfaction with EOL care

Diagnoses of interest: patients over age 55 with COPD, CHF, cirrhosis, metastatic cancer  
(all in advanced stages as defined in the protocol), patients  $\geq 80$  years old LTO<sub>2</sub>

# CANHELP Validation Study (con't)...

Target: 360 patients/360 caregivers nationally  
50-60 patients/50-60 caregivers (NBEMP).

To date: We have enrolled 45 patients and 32 caregivers.

*Positive feedback from NBEMP staff:*

*“Patients and families love your visits...chance for them to speak freely...chance to be heard (confidentially)”*

# **Attitudes to use of low-dose opioids for treatment of dyspnea in advanced COPD: A pilot study of Family Physicians and RRTs in NB**

(funded by AHSC(RHA2) Tier I Seed Grant – JY)

Objectives: (1) To explore the impediments (if any) to the use of low dose opioids for the treatment of dyspnea for patients with advanced COPD. (2) To explore what would be required to overcome impediments.

Target: 10 Family Physicians and 10 RRTs

To date: 1<sup>st</sup> pilot interview done with RRT.

Family Physician and hospital RRT booked  
before end of June 2008

# Attitudes to use of low-dose opioids for treatment of dyspnea in advanced COPD: A Study of Physicians in Nova Scotia

(funded by NSLA 2008)

Objectives: (1) To explore the impediments (if any) to the use of low dose opioids for the treatment of dyspnea for patients with advanced COPD. (2) To explore what would be required to overcome impediments.

Target: 30 Physicians (Family Medicine (5-10), Internal Medicine (5-10), Respiriology (5-10) and Palliative Medicine (5-10))

To date: to start September 2008

# Networking...

Apr/ Nov 2007	CARENET/FCGNET meeting, Montréal
May 2007	JY presentation, Advanced Learning in Palliative Medicine Conference, Halifax
May 22, 2007	“Defining Moments: End of Life care in the back of a truck” CMAJ
June 2007	GR presentation re: NIV to staff, Charlotte County Hospital, St. Stephen, NB
Nov 29, 2007	GR/JY presentation, Breathlessness Interventions in Canada: An Evolving Model, Cambridge University, UK
Feb 2008	GR presentation, Innovative Approaches and Supportive Care (COPD), American Academy of Hospice and Palliative Medicine, Tampa, FL
April 2008	GR presentation, PEI Medical Society, Grand Rounds, Summerside, PEI
April 15/16, 2008	GR (4 presentations), McGill – Jane Poulson visiting professor (EOL care), Grand Rounds, Montréal
May 2008	JY presentation, Advanced Learning in Palliative Medicine Conference, Ottawa
May 2008	GR presentation/ JY poster, NBART Educational Forum, Fredericton, NB
May 2008	GR presentation/ JY poster, American Thoracic Society, Toronto
September 2008	GR/ Irene Higginson(UK)/ JY, Breathlessness workshop, McGill International Congress on Palliative Care

# What's next?

## Continue to inspire a culture of research

“This research is exciting...we're happy for you and us professionally...feels like you're taking us with you on this journey...”

“I truly want to help...you don't need to thank me so much...just let me know what I can do”

“You guys are definitely the team to get this stuff done”

# New projects

## 1. Hospital admission for exacerbations of advanced COPD in a rural setting: A Longitudinal Cohort study in New Brunswick

- Objectives:
- (1) determine incidence, components, and value(from patient/family perspectives) of the discharge plan and continued care post index admission for AECOPD.
  - (2) determine the feasibility of enrolling patients in a 2 year longitudinal community-based in rural and urban settings in the Maritimes after hospital discharge for AECOPD.



# New projects

## **1. Hospital admission for exacerbations of advanced COPD in a rural setting: A Longitudinal Cohort study in New Brunswick**

Collect repeated measures of symptoms, medication and patterns of referral (patients); HRQoL, patients' perspectives on hope/uncertainty, prevalence and severity of anxiety and depression, satisfaction with care (patients and caregivers) and utilization of acute care services

# 1. Longitudinal NB study (con't)...

We will establishing a cohort of patients who are admitted to community hospitals in RHA2 with AECOPD.

For this to be effective:

- collaborative approach with other members of the Dal ICE-NELS team who can bring database expertise to the proposed NB rural setting.

Our increased understanding of care of advanced COPD in a rural setting with access to an established multi-disciplinary team (NBEMP) will provide comparative data and opportunities for future collaborative research and thus illuminate and extend similar efforts in the NS setting.

## 2. Implementation of COPD IMPACT within NBEMP? (Rocker G et al., CIHR funded 2006)

- For patients with mod-severe COPD as per CTS criteria
- Living Well with COPD (7 Modules) patient education/self-management program
- EOL care module (module 8)
- Education delivered by COPD Educator + Advanced care team community follow-up
- Measuring dyspnea, caregiver exp., satisfaction, ESAS, HRQoL, utilization....

NBEMP currently has no formal educational intervention (RRT discretion)

We would appreciate your  
questions/feedback

“Thank You”

Graeme Rocker/Joanne Young  
Dalhousie University/NBEMP  
Collaboration