

Adventures in Trans Atlantic palliative care research – using experience to navigate around icebergs

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Objectives

- Describe progress in overcoming challenges in palliative care research
- Demonstrate why the glass is half full
- Set the stage for the first Trans Atlantic crossing of the PRC international seminar

Challenges with palliative care research in the early years

- Palliative care lacks a firm knowledge base in many areas
- Providing such a base faces many challenges including organizational issues, research funding, design, methods and materials
- These are all accentuated when conducting multicenter projects and especially so if they cross firm borders





Where did your adventure begin?

- Seeds of Montebello 1988



1988 Montebello

- Sponsored by Canadian government
- Neil MacDonald report J of PC 1989
- Advocate re-allocate resources to EOL care to improve QOL without increasing costs
- Advocate NCIC improve funding for pain & symptom research
- Participant list Fainsinger before Foley

MacDonald J of PC 1992 Research – a neglected area of PC

- Need economic studies & health economist collaboration
- Develop international classification systems for cancer pain & other symptoms
- Integrate other disciplines e.g. basic scientists

Milestones

- Oct 1990 – 1st EAPC meeting in Paris
- 1991 D. Doyle – predicted the need for smaller research conferences
- 1992 G. Ford – need research for evidence “we believe is there but cannot yet provide”
- 1993 R. Twycross – need to replace anecdote & opinion with research
- Mount 1994 – recession & debt with failed advocacy “sink like a stone beneath the waters of change that are upon us”

OPIOID ROTATION FOR TOXICITY REDUCTION IN TERMINAL CANCER PTS

DE STOUTZ et al JPSM 1995;10:378

- 80/191 PTS HAD OPIOID ROTATION
- COGNITIVE FAILURE 39%
- HALLUCINATIONS 24%
- MYOCLONUS 11%
- UNCONTROLLED PAIN 16%
- NAUSEA 9%

ESS & OPIOID ROTATION(OR)

PAIN STAGE	OR	NO OR
0	0	4(4%)
1	43(34%)	84(73%)
2	2 (3%)	2(2%)
3	35(43%)	21(19%)

P = 0.001

Bristol experience

- 149 referrals to a Hospital-based palliative care team in UK
 - 57/138 pts had confusion
 - 13/57 pts confusion related to opioids
 - 11/13 pts responded to opioid dose reductions
- Hawley P, Hanks G. Pall Med 1997*

OPIOIDS, CONFUSION & OPIOID ROTATION

FAINSINGER RL, TORO R
PALLIATIVE MEDICINE
1998;12(6)

	RAH	PCU	p VALUE
AGE	71 ±12	62 ±13	<0.001
DAYS Rx	7 ±6	25 ±28	<0.001
ESS	0 18%	0 2%	<0.001
	1 26%	1 8%	
	2 46%	2 24%	
	3 10%	3 66%	
MEDD (day prior to death)	34 ± 49	145 ± 301	0.03

New Milestones
Kaasa et al P.M. 2006. Methodological & structural challenges in PC research: how have we fared in the last decade?

Place	Year	Oral	Poster	Number
Berlin	2000	88	112	380
Lyon	2002	69	106	525
Stresa	2004	76	211	700
Venice	2006	115	365	1000

- Following needs identified:-**
- 1. Academic research groups within universities
 - 2. Critical mass of ID basic science & clinical research personnel
 - 3. Larger, randomized, clinical multi-center studies
 - 4. National initiatives targeted at developing PC research

- Palliative Care Research Initiatives**
- United Kingdom – June 2006 1.9 million pounds to 2 large research teams for 5 years
 - European PC Research Collaborative – 6 countries represented 1.8 million Euros, fall of 2006 for 3 years
 - USA – 2007 American Cancer Society & National PC Research Centre awarded \$1.5 million in research grants
 - CIHR – palliative care team grants

Australia – August 2007

- Senator Brett Mason
- Australia National PC conference in Melbourne
- PC Clinical Studies Collaborative
- National partnerships, clinical drug studies with economic analyses
- Capacity for other PC research



Why do we need research

- PROS
 - Clinical
 - Education
 - Administration
 - Improves QOL for patients & families & health care professionals
- CONS
 - No time
 - Patient burden
 - No money
 - No expertise

Edmonton Palliative Care Research Legacy 1986 - 2016

The University of Alberta Chair in Palliative Medicine

Neil MacDonald

- vision & advocacy

Eduardo Bruera

- ideas, innovation, energy, research productivity

Vickie Baracos

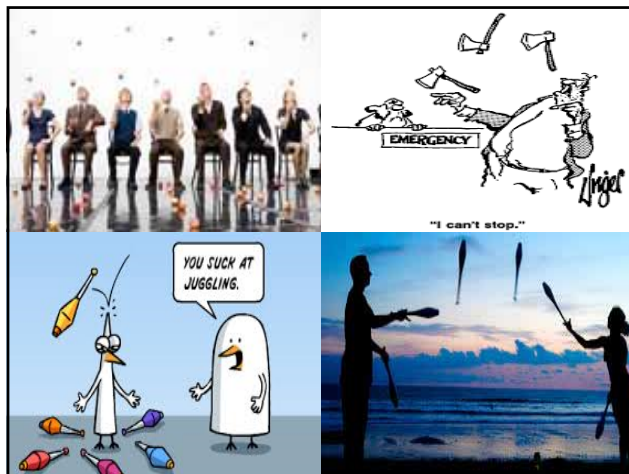
- Skilled basic scientist & cachexia research theme

- “there was darkness in the world & then there was light”



National/International Collaboration

- Requires personnel
- Research expertise
- Administrative support
- Adequate funding
- Communication – tele/video conferences, travel, websites
- Complex structures
- More time on meetings – talk vs action



Pharmacovigilance studies - metoclopramide (12 centers)
 - haloperidol and delirium (14 centers)
 - gabapentin and neuropathic pain (42 centers)

David Currow

Edmonton Classification for Cancer Pain – 2000 to present

- Alberta Cancer Board Palliative Care Research Initiative
- CIHR - 3 grants
- European Palliative Care Research Collaborative
- Caritas Research Fund
- Covenant Health Palliative Institute
- 24 publications

Nekolaichuk C, Fainsinger R



Publications 2010-2015

- Authors explicitly acknowledging PRC affiliation and publications from studies initiated by the PRC
- About 120 publications in international peer-reviewed journals
- Stein Kaasa

Canadian Pain Summit – Toronto 2016 Objectives

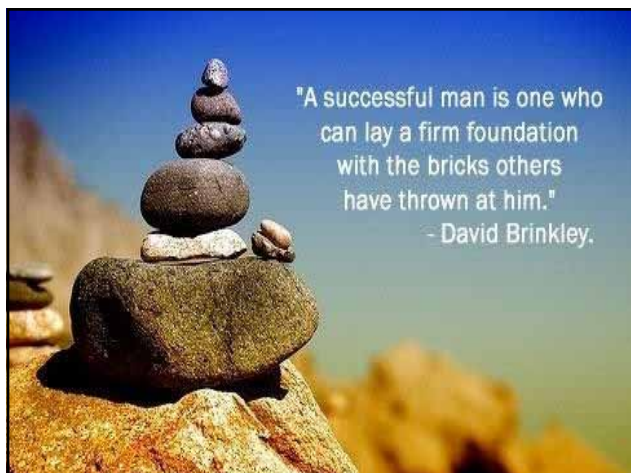
- Identify opportunities to enhance coordination of pain research across Canada
- Inform the development of a Canadian pain research agenda
- Encourage new collaborations and initiatives
- Positives – 1 PC MD at the meeting
- 2 1/2 days to get “Phenotyping and classification of cancer pain” on the agenda

Challenges with palliative care research

- Palliative care lacks a firm knowledge base in many areas
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Progress in challenges with palliative care research

- Palliative care has a growing firm knowledge base in many areas
- In providing such a base many challenges including organizational issues, research funding, design, methods and materials have been overcome
- Including when conducting multicenter projects even when they cross firm borders



A successful person is
one who can lay a firm
foundation with the
bricks that others throw at
him or her.

David Barclay

PICTUREQUOTES.COM

Developing PC Research Moving forward

- What are our clinical questions?
- What is our research question?
- What resources do we have &/or need to do the research?
- How can we develop an interdisciplinary research team?
- How can we take advantage of national & international collaborations?

- How can we use research to improve QOL for patients & families & Quality of Care delivered by our clinical programs?
- How do we continue to advocate & maintain funding?
- Good research takes time – this is (mostly) a team sport that is a marathon, not a sprint
- **Will not happen without a champion(s)**

Is the glass half empty or half full? A common expression, used to indicate a particular situation could be a cause for optimism (half full) or pessimism (half empty)





People who wonder if the glass is half empty or half full miss the point. The glass is refillable.

