IMPROVING PALLIATIVE CARE

Subtitle: Shaping public policy and enhancing care through

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DISCLOSURE

Dr. Hagen has no conflict of interest to report
Alberta

Alberta

The oil sand deposits lie under 141,000 square kilometres (54,000 sq. mi) of sparsely populated boreal forest and muskeg (peat bogs) and contain about 1.7 trillion barrels (270×10^9 m^3) of bitumen in-place, comparable in magnitude to the world's total proven reserves of conventional petroleum.
The University of Alberta Chairs in Palliative Medicine

Neil MacDonald  Eduardo Bruera  Vickie Baracos
Shaping public policy and enhancing care through a research agenda: what we learned

1. Initial experiences: Edmonton, Alberta

2. National experiences:
   * An advocacy group became mobilized
   * The Canadian Senate took action
   * The tipping point: the Canadian Institutes for Health Research was borne

3. Summary: lessons learned
In the 1980’s – 1990’s, an Edmonton based innovative research team in palliative care became highly impactful.

New knowledge and new approaches to assessing and managing palliative patients were taken up by clinicians around the world.

What does this experience teach us about knowledge transfer of research findings into clinical practice?
The Edmonton Symptom Assessment System (ESAS): A bibliometric study of global knowledge transfer

Greta G. Cummings RN PhD1
Neil A Hagen 2
Robin Fainsinger 3
Carla Stiles 2
Patricia Biondo 2

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2 Division of Palliative Medicine, Department of Oncology, University of Calgary; Tom Baker Cancer Center, Canada
3 Division of Palliative Care Medicine, Department of Oncology, University of Alberta, Canada
Background

Bibliometric methods analyze formal communications in the published literature, and patterns of publication within a field of study. This provides insight into the flow and uptake of knowledge over time in professional and other channels, and factors that promote or interfere with knowledge uptake. Application of bibliometric methods to palliative care can inform strategies to enhance knowledge transfer of best practices in end of life care.
Widespread uptake of innovations in palliative care can be supported through:

* targeting publication in high impact, international journals;
* explicitly focusing on applicability to best practice; -- research and clinical use *grew in parallel*
* consciously targeting key professional groups; and
* early translation and promotion in multiple languages.

... but how did assessment tools become *policy*? How is it that patients coming to cancer facilities in many parts of the world are now *required* to fill out validated symptom assessment tools?
In the 1980’s – 1990’s, an Edmonton based innovative research team in palliative care became highly impactful.
And then, another remarkable sequence of events occurred...
In the 1980’s – 1990’s, an Edmonton based innovative research team in palliative care became highly impactful.

And then, another remarkable sequence of events occurred...

Public health care policy in the province of Alberta dramatically changed its course.
In 1994-1996 due to a massive provincial government deficit, the publicly funded health care system dissolved its hospital-based structure and reorganized into 17 population-based Regional Health Authorities.

- The health care budget shrank by over 20%.
- A 960 bed general hospital was decommissioned.
Palliative and end of life programs became promoted as a means to assure high quality care without the high cost of acute care bed use.

AND

Provincial research dollars targeting palliative and end of life care dramatically increased.
Population-based, multi-sector palliative and end of life programs were established across Edmonton and Calgary. They continue to grow to this day.

Palliative and end of life programs each include:
- about 100 beds in residential, community based hospices
- multidisciplinary palliative and end of life care teams in each acute care facility; there are hospital-based intensive palliative care units
- comprehensive care in community based programs
- continuing care facilities have consultation teams
The introduction of comprehensive and community-based palliative care services resulted in:

* increased palliative care service delivery and
* cost neutrality, primarily achieved through a decreased use of acute care beds

Conclusion: The introduction of comprehensive, integrated, community-based palliative care programs was at no additional cost to the health care system.

And then, a second story played out nationally and was even more dramatic...
Canadian Cancer Society Report on the needs of people living with cancer in Canada

B. Adair, J Loveridge et al. 1986-1990

- pain was prevalent
- patients with pain often were receiving no analgesic medications
- of those receiving analgesics, they often did not work well
**Diffusion of Standards of Care for Cancer Pain**

* Tertiary cancer centres should routinely screen for pain and should have expert multidisciplinary pain clinics
* Faculties of Medicine should regard expertise in pain and symptom control as core undergraduate and post graduate curricular material
* Research funding agencies should establish processes to promote research in symptom control
The Special Senate Committee on Euthanasia and Assisted Suicide

Of Life and Death - Final Report

June 1995

http://www.parl.gc.ca/Content/SEN/Committee/351/euth/rep/lad-e.htm
PALLIATIVE AND END OF LIFE CARE RESEARCH IN CANADA

THE MEDICAL RESEARCH COUNCIL (MRC) becomes THE CANADIAN INSTITUTES FOR HEALTH RESEARCH (CIHR)

Senator Carstairs named as Minister with Special Responsibility for Palliative Care

Canadian Strategy for Cancer Control launched

Senate Report: Palliative and End of Life Care

National Cancer Institute of Canada: Workshop on Diffusion of Innovation

Report: Needs of Canadians Living with Cancer

CIHR Approach:
13 Research Institutes

Population and Public Health
Gender and Health
Nutrition, Metabolism and Diabetes
Musculoskeletal Health and Arthritis

Aboriginal Peoples’ Health
Genetics
Cancer Institute
Neurosciences, Mental Health and Addiction
Circulatory and Respiratory Health

Health Services and Policy Research
Infection and Immunity
Aging
Human Development, Child and Youth Health
PALLIATIVE AND END OF LIFE CARE RESEARCH IN CANADA

Phil Branton named as first Director of the CIHR’s Cancer Institute

- Senator Carstairs named as Minister with Special Responsibility for Palliative Care
- MRC becomes CIHR
- Canadian Strategy for Cancer Control launched
- Senate Report: Palliative and End of Life Care
- National Cancer Institute of Canada: Workshop on Diffusion of Innovation
- Report: Needs of Canadians Living with Cancer

Canadian Cancer Society

Delphi process employed to identify key national research priorities in cancer. Palliative and end-of-life care was identified as its top priority.

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National Cancer Institute of Canada: Workshop on Diffusion of Innovation

Report: Needs of Canadians Living with Cancer

Canadian Cancer Society

A STORY ABOUT A NATIONAL RESEARCH AGENDA SHAPING PUBLIC POLICY

- 19 Pilot Projects
- 10 New Emerging Team Grants
- 1 Career Transition Award

2003-2004: total investment was $16.5 million over six years (all for grant operations, salary support from elsewhere)
Delphi process employed to identify key national research priorities in cancer. Palliative and end of life care identified as its top priority.

- Phil Branton named as first Director of the CIHR’s Cancer Institute.
- Senator Carstairs named as Minister with Special Responsibility for Palliative Care.
- MRC becomes CIHR.
- Canadian Strategy for Cancer Control launched.
- Senate Report: Palliative and End of Life Care.
- National Cancer Institute of Canada: Workshop on Diffusion of Innovation.
A formal impact assessment of this research program was undertaken. It documents the impact of the initiative on palliative care research capacity across the entire country, as well as research productivity and quality, and identifies lessons learned on best practices to support such strategic initiatives.

http://www.cihr-irsc.gc.ca/e/41180.html
INCREASE IN NATIONAL RESEARCH CAPACITY IN PALLIATIVE CARE CONCURRENT WITH THE NATIONAL RESEARCH FUNDING INITIATIVE

Table 3.3: Canadian authors publishing palliative care research

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<tr>
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<th>1996-8</th>
<th>2001-3</th>
<th>2006-8</th>
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<tbody>
<tr>
<td>A. total authors</td>
<td>911</td>
<td>1189</td>
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<tr>
<td>B. number of publications</td>
<td>258</td>
<td>294</td>
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<tr>
<td>C. authors/publication</td>
<td>3.53</td>
<td>4.07</td>
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<tr>
<td>D. unique authors</td>
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<td>843</td>
<td>1532</td>
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<tr>
<td>E. % non-Canadian authors</td>
<td>N/A</td>
<td>~36%</td>
<td>~29%</td>
</tr>
<tr>
<td>F. Approximate size of Canadian PELC research community</td>
<td>N/A</td>
<td>540</td>
<td>1090</td>
</tr>
</tbody>
</table>

http://www.cihr-irsc.gc.ca/e/41180.html
By 2008 almost 40% of Canadian Palliative and End of Life Care research papers had one or more international authors.

The greatest numbers of collaborations are with the USA, followed more recently by the UK and Australia, presumably as a result of those countries launching their own Palliative and End of Life Care research initiatives.
What did the initiative accomplish?

- Nationally increased both the quantity and quality of PELC research.
- Developed strong and effective partnerships with user communities, including decision-makers and patients.
- Is producing results that are being integrated into practice guidelines, health professional training, and policy discussions.
A SHIFT INTO MAIN STREAM PUBLIC POLICY: SCREENING FOR DISTRESS

Screening for distress in lung and breast cancer outpatients: a randomized controlled trial

Carlson LE, Groff SL, Maciejewski O, Bultz BD
Tom Baker Cancer Centre, Calgary, Alberta, Canada.
l.carlson@ucalgary.ca

Cancer Journey Action Group

Guide to Implementing Screening for Distress, the 6th Vital Sign

Moving Towards Person-Centered Care

Part A: Background, Recommendations, and Implementation

MAY 2009
Symptom Management Tools

These tools help healthcare providers monitor and manage their patients' symptoms more effectively, regardless of where they are in their cancer journey.

**NEW!** Managing Shortness of Breath, a video series for patients — View now on YouTube

Edmonton Symptom Assessment System (ESAS)

A valid and reliable assessment tool to screen for the intensity of nine common symptoms experienced by cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath.

Patients can report their ESAS scores electronically at many regional cancer centres using ISAAC. Find out more about ISAAC (Interactive Symptom Assessment and Collection)

- [ESAS - Edmonton Symptom Assessment System - Description](#)
- [Instructions à l'intention des patients Échelle d'évaluation des symptômes d'Edmonton ESSE](#)

**ESAS Tool** - Select a language

**Note:** You must allow pop-ups in your browser to download these files.

Symptom Management Guides
Cancer Care Ontario Symptom Management Guides

By Cancer Care Ontario

Open iTunes to buy and download apps.

Description
Symptom Management Guides - developed through the Ontario Cancer Symptom Management Collaborative, an initiative of Cancer Care Ontario (CCO) - assist health care professionals in the assessment and appropriate management of a patient’s cancer-related symptoms.

What’s New in Version 1.3
Allow customers with earlier versions of iOS (i.e. Verizon) to use the app.

iPhone Screenshots

Symptoms
- Pain
- Dyspnea

Care Pathways
- Mild (ESAS 1-3)
  - Patient not using analgesia effectively.
  - Mild pain not interfering with ADL’s.
Symptom Assessment

Percentage of cancer patients, excluding lung cancer patients, who were screened at least once per month for symptom severity, by cancer centre, 2009-2010

CCO Program Target 2010: 65%

Report Date: December, 2011
Data Source: Ontario Cancer Symptoms Management Reporting Database, Activity Level Reporting
Prepared By: Cancer Care Ontario, Cancer Informatics

CSQI 2011
OUTLINE

Shaping public policy and enhancing care through a research agenda: what we learned in Canada

1. Initial experiences: Edmonton, Alberta

2. National experiences:
   * An advocacy group became mobilized
   * The Canadian Senate took action
   * The tipping point: the Canadian Institutes for Health Research was born

3. Summary: lessons learned
1. Innovation in palliative and end of life research shapes a culture of excellence in health care delivery and shapes local national public expectations. It can be foundational to major public policy changes.

2. There is a very high level of interest in innovative methods to improve care by researchers and health care providers, but also by public policy makers.

3. Bringing about formative change often requires recognizing that the system is close to a tipping point – then bringing researchers, clinicians and policy makers alike together – and identifying explicit win-win scenarios to promote public policy that improves care.
IMPROVING PALLIATIVE CARE THROUGH A RESEARCH AGENDA

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