Pain Assessment in Dementia: Clinical Challenges, Applications and Innovation

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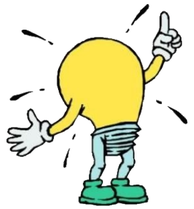
at the UNIVERSITY OF REGINA

The Problem of Pain in Dementia

- Pain is subjective and its assessment relies on self-report
- People with severe dementia have compromised ability to report pain
- Pain is undertreated in this population
- Pain can manifest as behavioural disturbance which can be misattributed to a psychiatric problem



All I had to do:

- Identify non-verbal expressions of pain through video analysis in the lab
- Develop a clinically useful tool
- Everyone will use it!
- Problem solved!

PARADIGM SHIFT

Researcher in the lab

Research question

Laboratory Study

Publication in the scientific literature

Lost in translation?

17 years

Maybe implementation

Emphasis on real-world problems and outcomes

Problem

Knowledge users/patients ⟷ Researchers

Research questions

Research in lab ⟷ Field research

Policy briefs

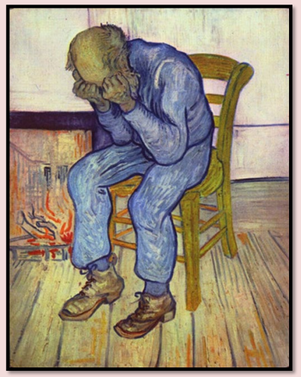
Economic impact research

- Publication in the literature
- Knowledge mobilization
- Policy makers

Implementation Science
(a nonlinear process) / Emphasis in interdisciplinarity

A Program of Research

- Laboratory Investigations
- Development & Evaluation of Clinically Useful Tools
- Development of Clinical Consensus Guidelines
- Existential Crisis & Questioning Career Choices
  - Public Policy Research
  - Implementation Science
  - Costing Research
  - Patients as Partners
  - Online Training Development
  - Technology Development
  - Innovative Approaches to Knowledge Dissemination



(Vincent Van Gogh, *Eternity's Gate*, 1890)

Laboratory-Dependent Investigations

Facial Action Coding System (FACS)

(Ekman & Friesen, 1978; Prkachin & Solomon, 2008)

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(Ekman & Friesen, 1978; Prkachin & Craig, 1985)

Pain Behaviour Measurement (PBM)

Guarding

Bracing

Grimacing

Sighing

Rubbing affected area

(Keefe & Block, 1982)

Summary of Findings

- ✓ Increases in facial activity and other pain behaviours in response to painful medical procedures and as a function of movement exacerbated pain.
- ✓ No major group differences based on cognitive status
- ✗ Systematic coding useful for research but too cumbersome for clinical practice

(Hadjistavropoulos et al., 1997; 1998; 2000; 2002)

Development & Evaluation of Clinically Useful Tools

The PACSLAC-II

Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II)	
Date of Assessment: _____ Time: _____	Check if present
Facial Expressions	
1. Grimacing	
2. Tighter face	
3. Pain expression	
4. Increased eye movement	
5. Wincing	
6. Opening mouth	
7. Creasing forehead	
8. Lowered eyebrows or frowning	
9. Raised cheeks, narrowing of the eyes or squinting	
10. Wrinkled nose and raised upper lip	
11. Eyes closing	
Verbalizations and Vocalizations	
12. Crying	
13. A specific sound for pain (e.g., 'ow', 'ouch')	
14. Moaning and groaning	
15. Grunting	
16. Gasping or breathing loudly	
Body Movements	
17. Flinching or pulling away	
18. Thrashing	
19. Refusing to move	
20. Moving slow	
21. Guarding sore area	
22. Rubbing or holding sore area	
23. Limping	
24. Clenched fist	
25. Going into foetal position	
26. Stiff or rigid	
27. Shaking or trembling	
Changes in Interpersonal Interactions	
28. Not wanting to be touched	
29. Not allowing people near	
Changes in Activity Patterns or Routines	
30. Decreased activity	
Mental Status Changes	
31. Are there mental status changes that are due to pain and are not explained by another condition (e.g., delirium due to medication, etc.)?	
TOTAL SCORE (Add up checkmarks)	

Clinical Utility of the PACSLAC

Experimental Group

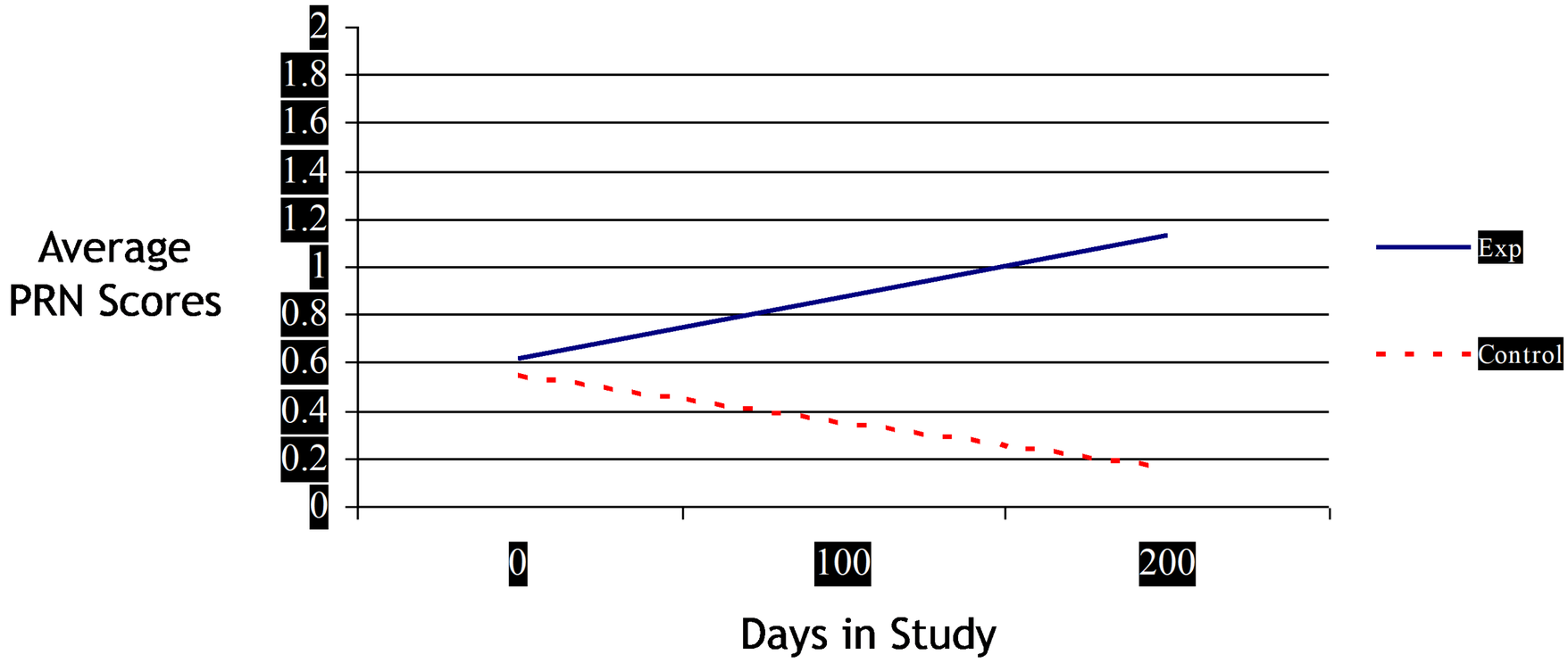
- Nurses to Assess Pain Using the PACSLAC

Control Group

Nurses to Complete a Non-Pain Relevant Checklist

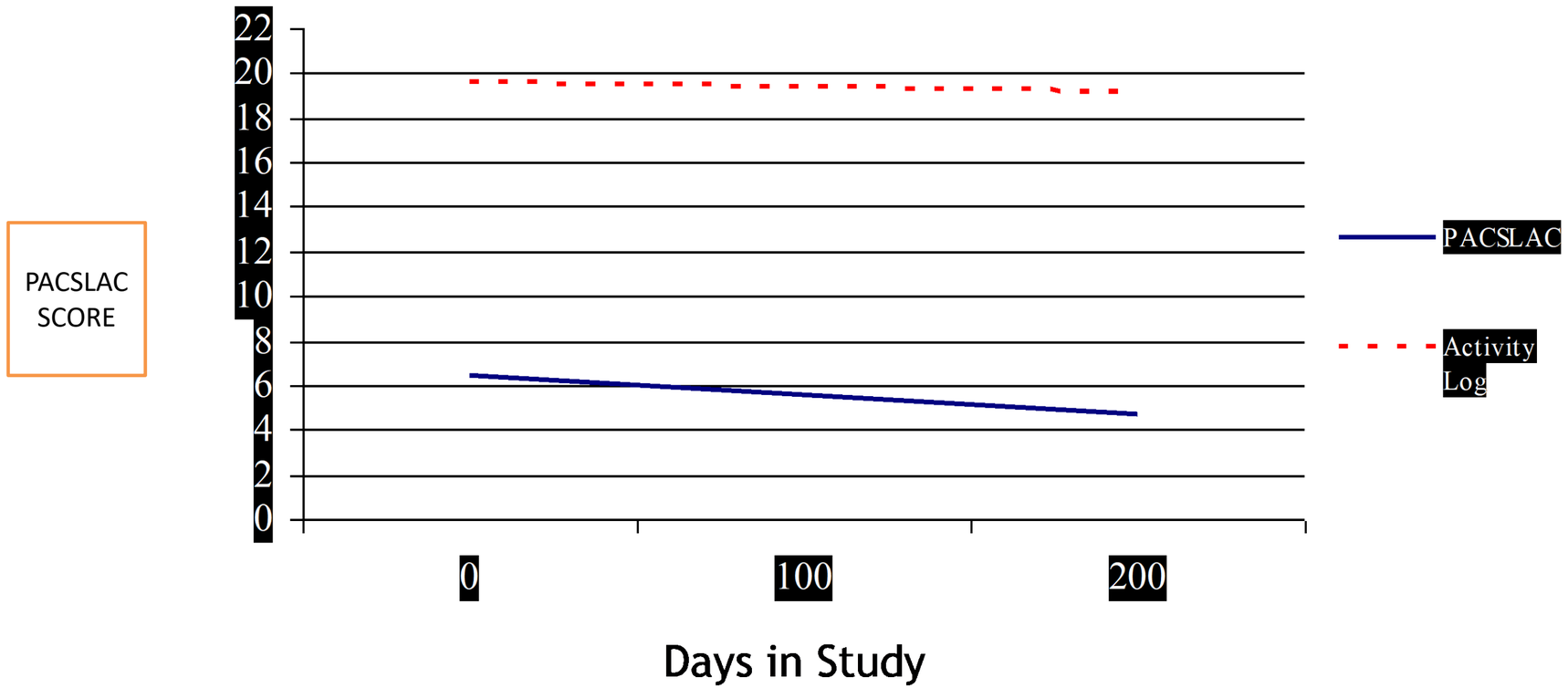
(Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008)

Average PRN Pain Medication Score Change Over Time for Patients in the Experimental & Control Groups



(Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008)

Average Pain/Checklist Score Change Over Time for Patients in the Experimental & Control Groups



Using the Maslach Burnout Inventory (MBI), nurse stress and burnout scores in the experimental group showed statistically significant reductions over time whereas those of the control group did not.

(Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008)

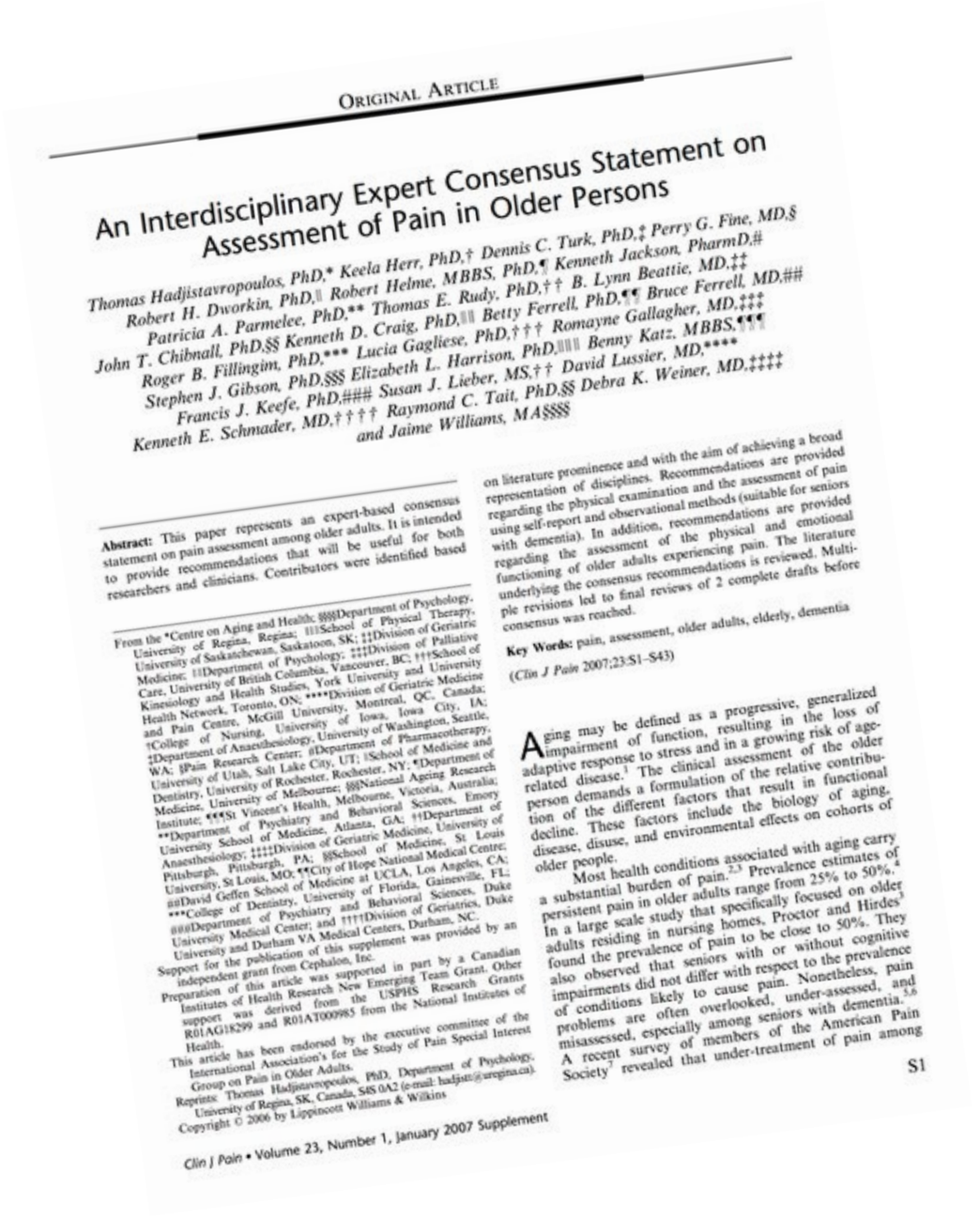
Reducing Unnecessary Polymapharmacy with Effective Pain Assessment

Number of benzodiazepine medications prescribed

	Baseline	Post
PACSLAC-II Group	*M* = .22 (SD = .51)	*M* = .15 (SD = .46)
Control Group	*M* = .22 (SD = .55)	*M* = .44 (SD = .92)

(Hadjistavropoulos et al., 2014)

Development of Clinical Consensus Guidelines



ORIGINAL ARTICLE

An Interdisciplinary Expert Consensus Statement on Assessment of Pain in Older Persons

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Abstract: This paper represents an expert-based consensus statement on pain assessment among older adults. It is intended to provide recommendations that will be useful for both researchers and clinicians. Contributors were identified based on literature prominence and with the aim of achieving a broad representation of disciplines. Recommendations are provided regarding the physical examination and the assessment of pain using self-report and observational methods (suitable for seniors with dementia). In addition, recommendations are provided regarding the assessment of the physical and emotional functioning of older adults experiencing pain. The literature underlying the consensus recommendations is reviewed. Multiple revisions led to final reviews of 2 complete drafts before consensus was reached.

Key Words: pain, assessment, older adults, elderly, dementia

(*Clin J Pain* 2007;23:S1–S43)

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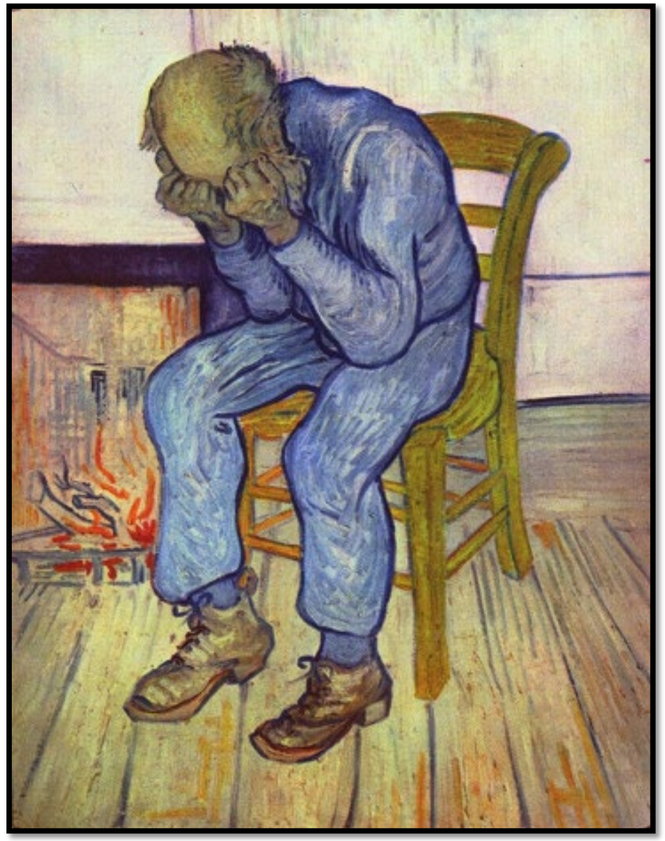
Aging may be defined as a progressive, generalized impairment of function, resulting in the loss of adaptive response to stress and in a growing risk of age-related disease.[1] The clinical assessment of the older person demands a formulation of the relative contribution of the different factors that result in functional decline. These factors include the biology of aging, disease, disuse, and environmental effects on cohorts of older people.

Most health conditions associated with aging carry a substantial burden of pain.[2,3] Prevalence estimates of persistent pain in older adults range from 25% to 50%.[4] In a large scale study that specifically focused on older adults residing in nursing homes, Proctor and Hirdes[5] found the prevalence of pain to be close to 50%. They also observed that seniors with or without cognitive impairments did not differ with respect to the prevalence of conditions likely to cause pain. Nonetheless, pain problems are often overlooked, under-assessed, and misassessed, especially among seniors with dementia.[5,6] A recent survey of members of the American Pain Society[7] revealed that under-treatment of pain among

Existential Crisis & Questioning Career Choices



(Vincent Van Gogh, Eternity's Gate, 1890)

Public Policy Research

- We asked a question…
  - If we know how to assess/manage pain in LTC, why isn't there wide adoption of existing guidelines?

Answer from Public Policy Experts

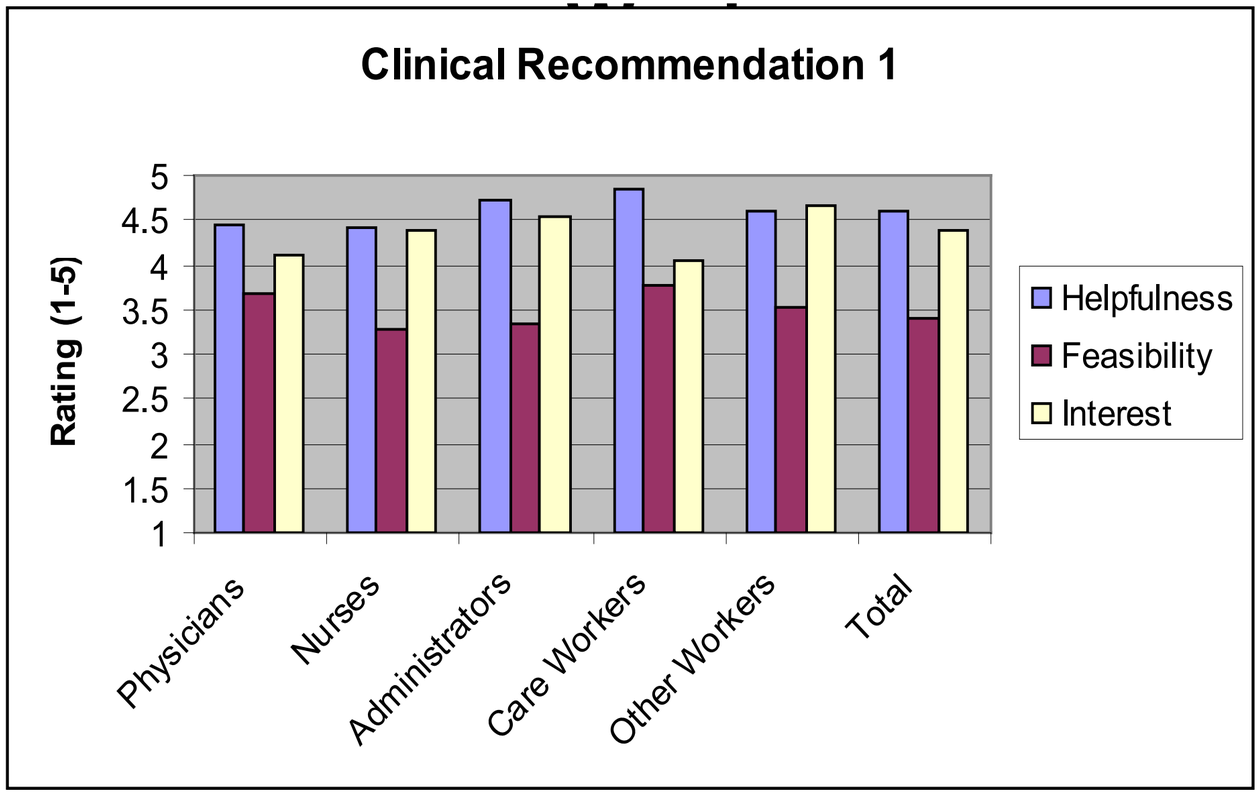
- You want everyone to have the Rolls Royce of pain assessment/management, but nobody can afford it

A More Sensible Solution

- Assess everyone on admission
- Minimum 1 brief assessment per week
- Intervention within 24 hours
- Re-assess after 24 hours

(Hadjistavropoulos et al., 2009)

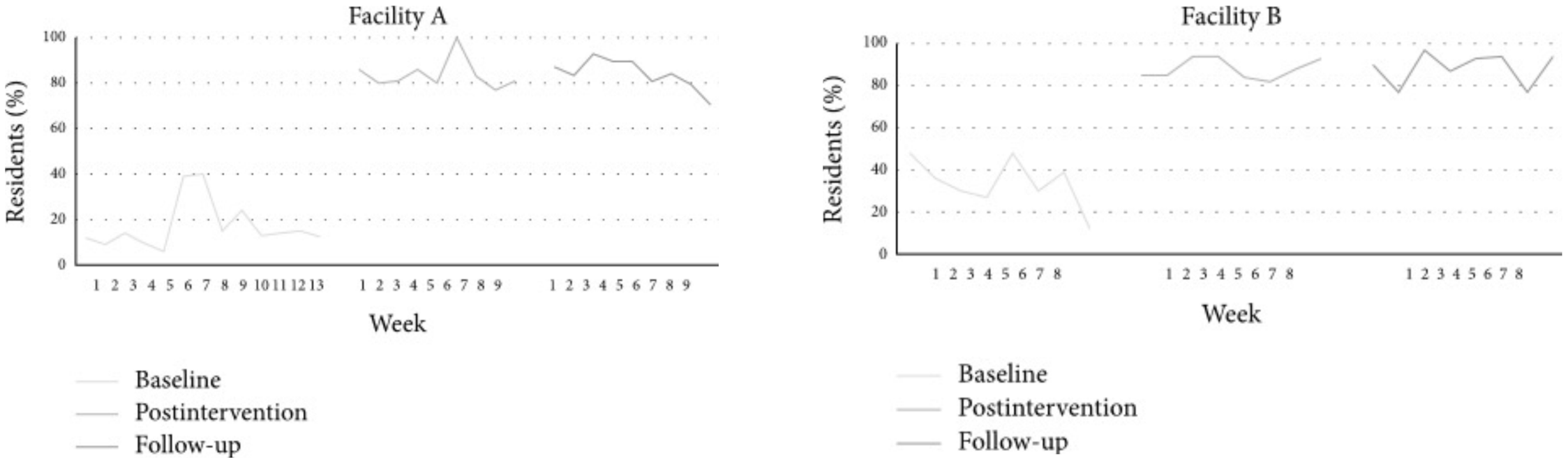
All LTC Residents Will Have Pain Assessed within 24 Hours of Admission and No Less Frequently Than Once



(Hadjistavropoulos et al., 2009)

Implementation

Use of Assessment Tools



Note. The percentages for Facility A are based on a total resident population of = 121–127 (resident population varied slightly from week to week). The percentages for Facility B are based on a total resident population of = 29–33 (resident population varied slightly from week to week).

(Hadjistavropoulos et al., 2016)

Costing Research

Pain, Cost and Health Care Utilization in LTC

24,870 Saskatchewan LTC residents between 2004 and 2015

CSP (Clinically significant pain) group	Control Group
$8063 CAD	**$6455 CAD**

- Higher hospitalization, physician visits, and prescription drug costs, and polypharmacy

***Similar results were obtained after controlling for demographics, comorbidities, physical and cognitive impairment, prior health care costs, and facility characteristics**

(Guliani, Hadjistavropoulos et al., 2020; Guliani, Hadjistavropoulos et al., 2021)

Technology Development

Mike Reily formerly of the Edmonton Eskimos and BC Lions

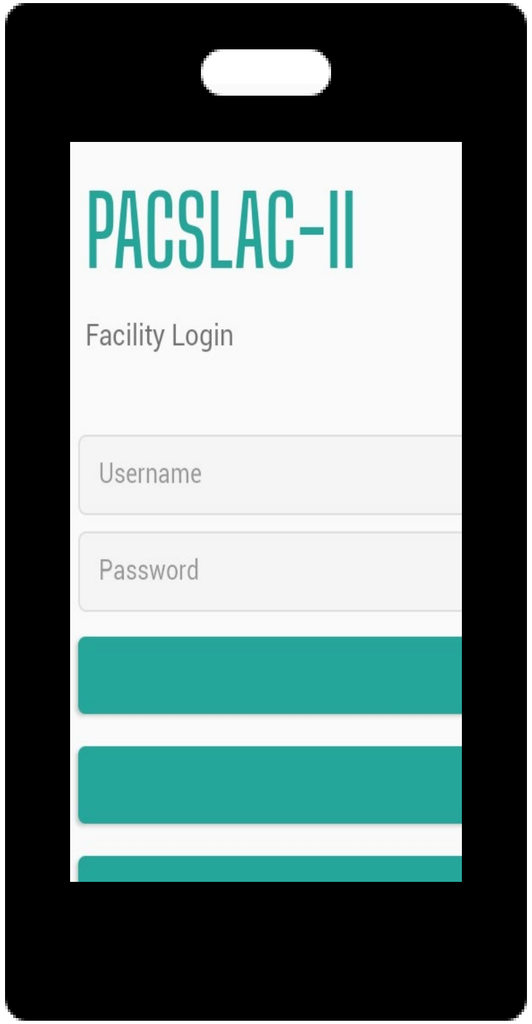
Alex Mihailidis, Ph.D

“Over the course of our lifetime, the best solutions to the problems of Alzheimer’s Disease and other dementias will not come from the medical sciences but from *technology development*.”

Uses of Technology

- Interactive online training for rural LTC staff
- PACSLAC-II app
- Computer vision to monitor pain behaviours
- Use of internet and social media for KT

Evaluation of the PACSLAC-II App vs Paper



(Zahid, Hadjistavropoulos et al., 2020)

Quality Indicators (online training): % assessed minimum once a week with standardized tool

Facilities	Pre	Post
A	7%	67%
B	76%	81%
C	0%	89%
D	0%	98%
E	5%	18%
F	0%	35%
G	11%	100%

Gallant, Hadjistavropoulos et al. (in press)

WP 6.3—Development & Evaluation of an Automated System to Assess Pain in Dementia

- The system would overcome human resource limitations
- Based on monitoring of pain behaviours, the system will alert staff when pain is suspected
- The system creates the tantalizing possibility of continually monitoring pain behaviours

Hadjistavropoulos et al. (2018)

Computer Vision Development Work

- We videorecorded patients with and without dementia from three different angles of observation
- We coded that data using FACS and the PACSLAC-II
- More than 1,060,000 frames have been coded (~5000 frames per each baseline and painful segment, for 106 participants)

Babak Taati,
Toronto Rehab Institute

Automatic Pain Detection

Pain Detection Accuracy

	False Positive Rate	True Positive Rate	False Negative Rate	True Negative Rate	Cut-off scores
1	15%	**70%**	30%	85%	0.80
2	32%	**85%**	15%	68%	0.41
3	45%	**89%**	11%	55%	0.29
4	46%	**91%**	7%	54%	0.29
5	61%	**95%**	5%	39%	0.24

Taati et al. (2020)

People with Lived Experience as Partners

Mary Brachaniec
Caregiver Partner

Phase 1 Results: #SeePainMoreClearly Initiative

(5-month evaluation: October 1, 2019 to February 28, 2020)

#SeePainMoreClearly Twitter

- 5,748,917 impressions
- 2,376,853 unique users
- 2,905 hashtag mentions
- 31 countries

2-minute informational YouTube video

- 50,000 views
- 150,578 impressions
- viewed by 48,861 individuals

seepainmoreclearly.org website

- 5,751 website visits
- 1,218 individuals
- 55 countries

10 media stories (e.g., CBC, CTV Regina Live, CIHR, Leader Post, Global News, Relief Magazine)

Conclusions

- Paradigmatic shifts in health care research increasingly emphasize the importance of knowledge translation, knowledge mobilisation and partnerships with stakeholders.
- Tackling complex, real world problems can lead clinical health scientists to areas of research that were previously foreign to them
- Effectively addressing pain in dementia requires a combination of basic and clinical science, public policy and KT effort, implementation science, engineering, computer science, patient partners…

The Lab

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