Toronto Rehab Brain and Spinal Cord
LEAP Service
Living Engaged and Actively with Pain

What is the Impact of a Pain Management Group for People with Neurological Conditions and Persistent Pain?
A Pilot Study

UHN
Toronto General
Toronto Western
Princess Margaret
Toronto Rehab
Michener Institute

Presenters

- J. Bronwen Moore, OT
  - TRI - UHN, LEAP Service, Adjunct Lecturer at University of Toronto Department of Occ. Science and Occ. Therapy
- Sarah Sheffe, OT
  - TAPMI – Women's College Hospital, Adjunct Lecturer at University of Toronto Department of Occ. Science and Occ. Therapy
- Unable to attend: Laura Langer, Biostatistician
  - KITE Research Institute

Conflict of Interest Declaration

- The speakers have no conflict of interest to report
- The workbook and website that the team created are revenue-generating, and all proceeds go to the UHN Foundation

Study investigators

- Sarah Sheffe, OT
- Bronwen Moore, OT
- Laura Langer, Biostatistician
- Cara Kircher, OT
- Bonnie Cai-Duarte, PT
- Ella Huszti, Biostatistician
- Yidi Jiang, Biostatistician
- Janelle Panday, M.Sc., Research Analyst
- Debbie Hebert, OT, PI (deceased March 19, 2020)

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- Allison Freeman, OT, Former Program Manager & Sarah Munce, Research Scientist

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CAP
COLLABORATIVE ACADEMIC PRACTICE

UHN
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Princess Margaret
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Michener Institute

Objectives

Participants will learn about:

1. The connection between brain injury and pain
2. Evidence for the effectiveness of pain self-management education for clients with brain injury
3. A Pain Management Group designed specifically for clients with brain injury and other neurological conditions
4. Results of a research project that evaluates the effectiveness of this treatment program
5. Practice tips for working with pain and brain injury

ABI AND PAIN

Definition of Pain

- “An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.”
- “Pain is always personal, and the person’s report of an experience as pain should be respected”
- “Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being” (Raja et al., 2020)

Pain and ABI

- More than half of patients with ABI experience pain (Khoury & Benavides, 2018); Nampiaparampil, 2008)
- Pain linked to negative effect on rehab outcomes:
  - Reduces engagement in rehab activities
  - Pain anxiety leads to fear and avoidance of movement
  - Higher rates of mood disorders, distress
  - Reduced density of grey matter in prefrontal cortex and thalamus (executive function) (Williams, Rapport, Sander, & Parker, 2021)

- People with ABI report less control over pain than others
  - Due to cognitive changes, decreased insight and mood disorders (Dahm & Ponsford, 2015; Branca & Lake, 2004; Tyler & Lievesley, 2003)

Why worry about pain after ABI?

Misdiagnoses

- Symptoms of pain and ABI are similar – masking can occur

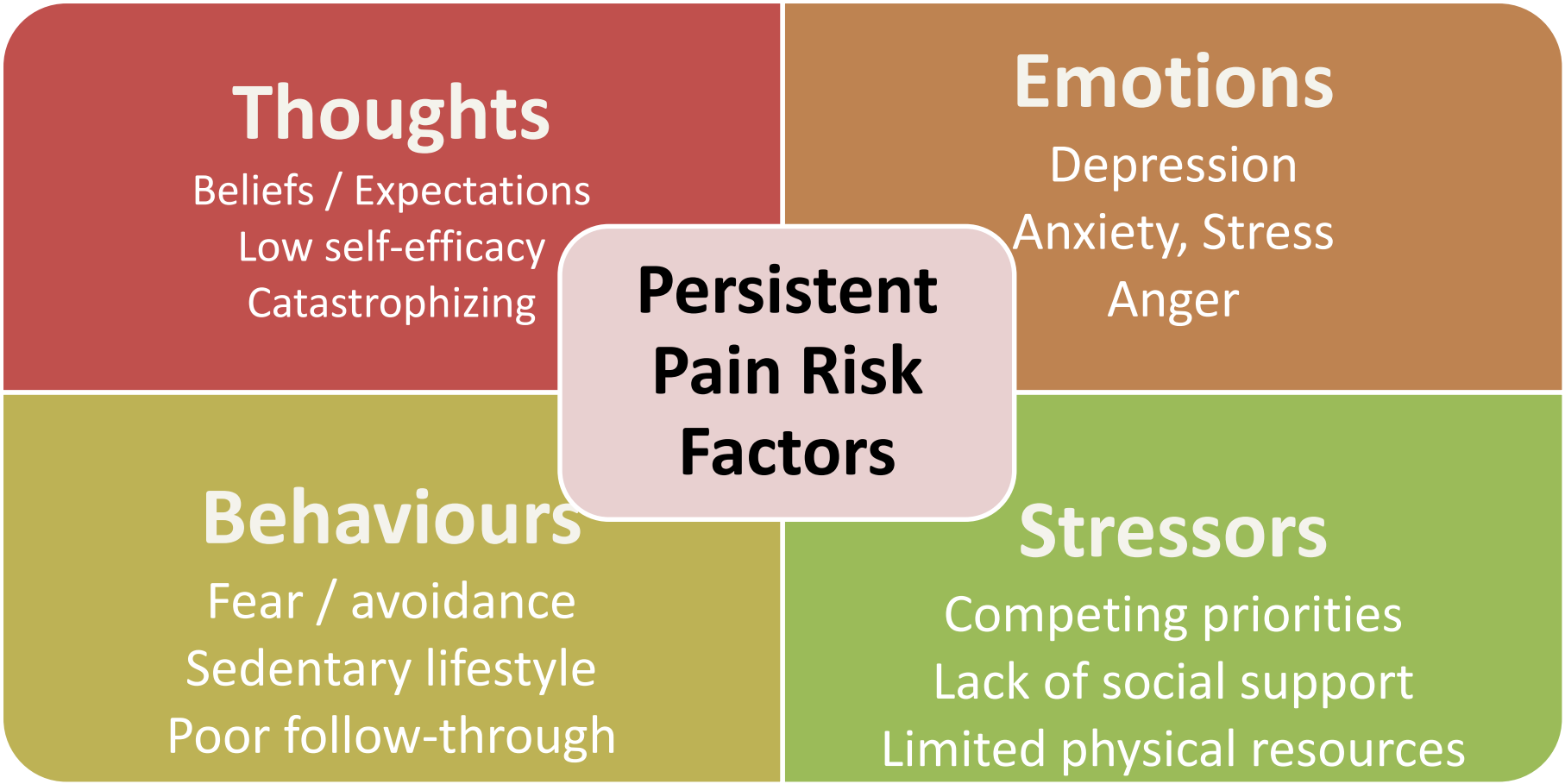
Impairment

- Physical
- Functional
- Psychological

Cognition

- Anticipation of pain disrupts cognitive efficiency

(Yilmaz et al., 2017; Iezzi, Duckworth, Mercer & Vuong, 2007; Martelli, Zasler, Bender & Nicholson, 2004)



(Mann, Lefort & VanDenKerkhot, 2013; Martelli, Zasler, Bender & Nicholson, 2004; Yilmaz et al, 2017)

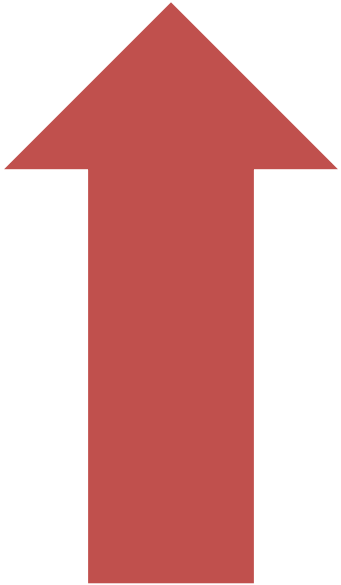
EVIDENCE FOR PAIN SELF-MANAGEMENT EDUCATION

Evidence for Pain Management Groups

- Group-based, interdisciplinary pain management education has been well established as effective intervention with many long term functional, health and psychological benefits (Katz, Paterson & Zacharias, 2019; Simm & Barker, 2017)

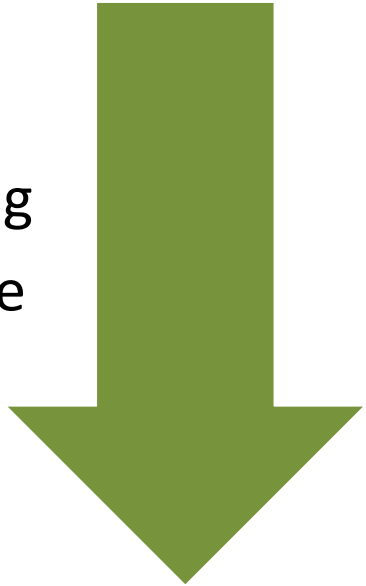
- Education about pain for adults with **ABI** associated with improved:
  - Participation in rehab
  - Outcomes
  - Anxiety and fear of movement (Williams, Rapport, Sander & Parker, 2021)

Self-management education works!



Increases

- Self Efficacy
- Cognitive coping
- Task persistence
- Acceptance
- Function
- Quality of life



Decreases

- Catastrophizing, anxiety
- Use of analgesics
- Healthcare access, emergency room visits, hospitalizations

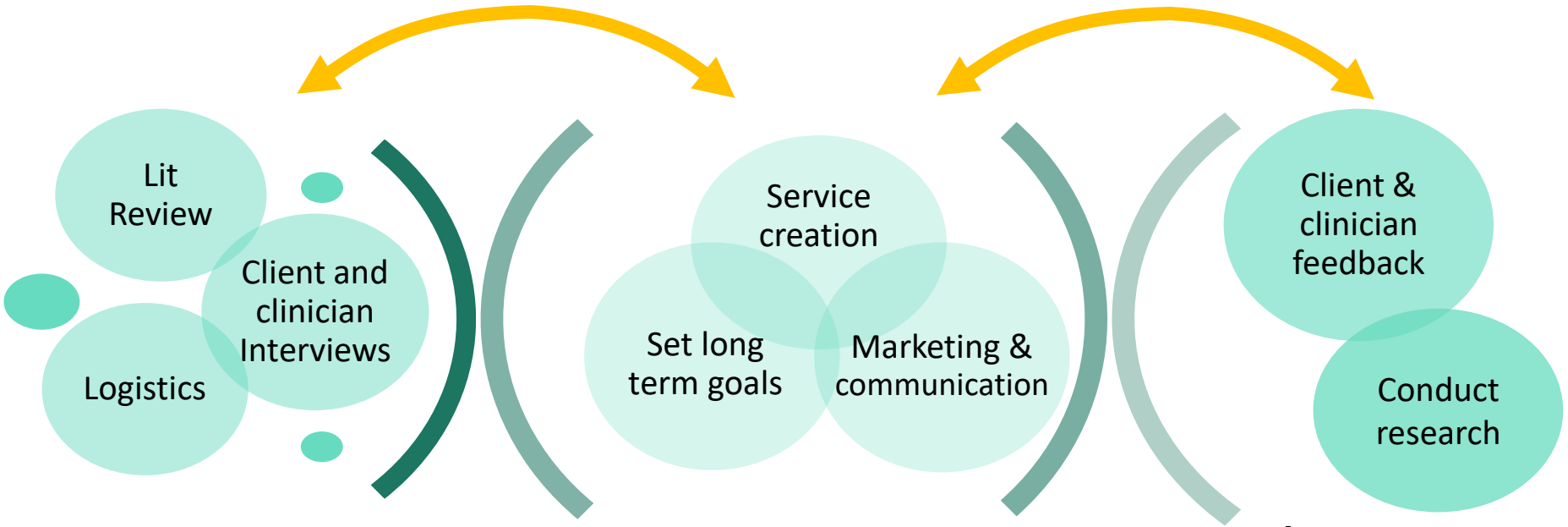
(Miller, MacDermid, Walton & Richardson, 2020; Hoffman et al., 2007; Mann, LeFort & VanDenKerkhot, 2013; Nash, Ponto, Townsend, Nelson & Bretz, 2013; Katz, Peterson & Zacharias, 2019)

Best pain coping skills

(Sommer & Witkiewicz, 2004; Iezzi, Duckworth, Mercer, & Vuong, 2007; Tyler & Lievesley, 2003)

LEAP PAIN MANAGEMENT GROUP

Development of Model



Planning

(Sept. 2014 – April 2015)

Integrating

(March 2015 – June 2015)

Evaluating

(June 2015 – Present & ongoing)

LEAP Pain Management Group (PMG)

1. Understanding pain
2. Doing what matters
3. Stress management and relaxation
4. Movement and physical activity
5. All about sleep
6. Thoughts and pain
7. Managing emotions
8. Assertive communication
9. Managing pain flare-ups

Meets once per week for 2 hours

Key elements of each session

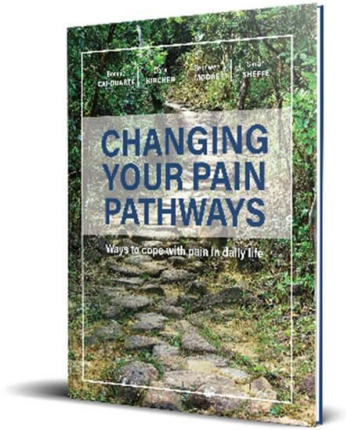
- Relaxation practice
- Teaching of topic:
  - What is it?
  - Why does it matter?
  - What can I do?
- Discussion and peer support
- Movement break: gentle exercises
- Values-driven goal setting
- Knowledgeable and supportive facilitators

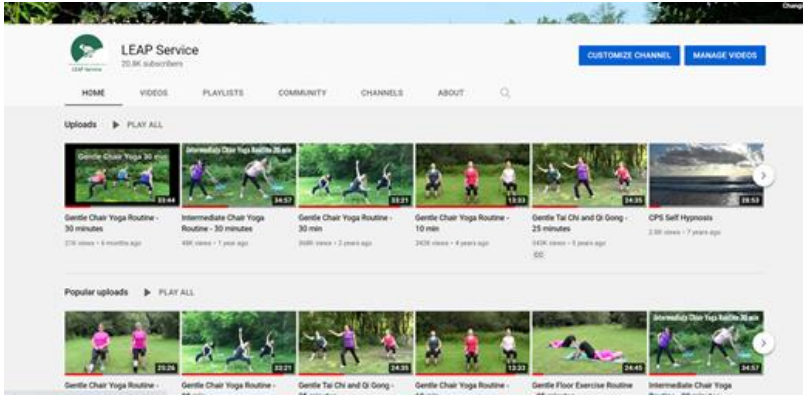
Adaptations for Clients with ABI

- Workbook – plain language
- Worksheets – checklists and options
- Multiple ways of learning
- Emphasis on physical / embodied practices
- Repeated practice of key skills and messages
- Options to review independently, e.g. workbook and videos

Additions since the study…

- Workbook
- Online videos
- Virtual care





RESEARCH PROJECT

Objectives of pilot study

- This mixed methods study explored the impact of the **LEAP Pain Management Group (PMG)** on psychological and functional outcomes for people with neurological disorders and pain.

- Supports a long term goal of disseminating the model of care to other facilities.

Canadian Pain Task Force Recommendations

Established goals for key areas of action to transform how pain is understood and treated (national consensus):

- Improve access to timely, equitable, and person-centred pain care
- Support pain research and strength related infrastructure
- **Ensure equitable approaches for populations disproportionately impacted by pain**

(Health Canada, 2021)

Methods

- REB Approved (16-6029-DE)
- Sample: Participants recruited over a 1 year time period at intake interview (prospective sample)
- Pre- and post-test design
- Testing at intake (T1), at end of group (T2) and at 4 month follow-up (T3)
- Sample: Recruited 53 participants; 44 joined the PMG; 35 attended 3 or more sessions; 33 had full data at T1 and T2; 9 had full data at all 3 time points

Outcome Measures

- Canadian Occupational Performance Measure (COPM)
- Numerical Pain Rating Scale (NPRS)
- Pain Catastrophizing Scale (PCS)
- Chronic Pain Acceptance Questionnaire (CPAQ)
- Rand 36-Item Short Form Health Survey (SF-36)

Analysis

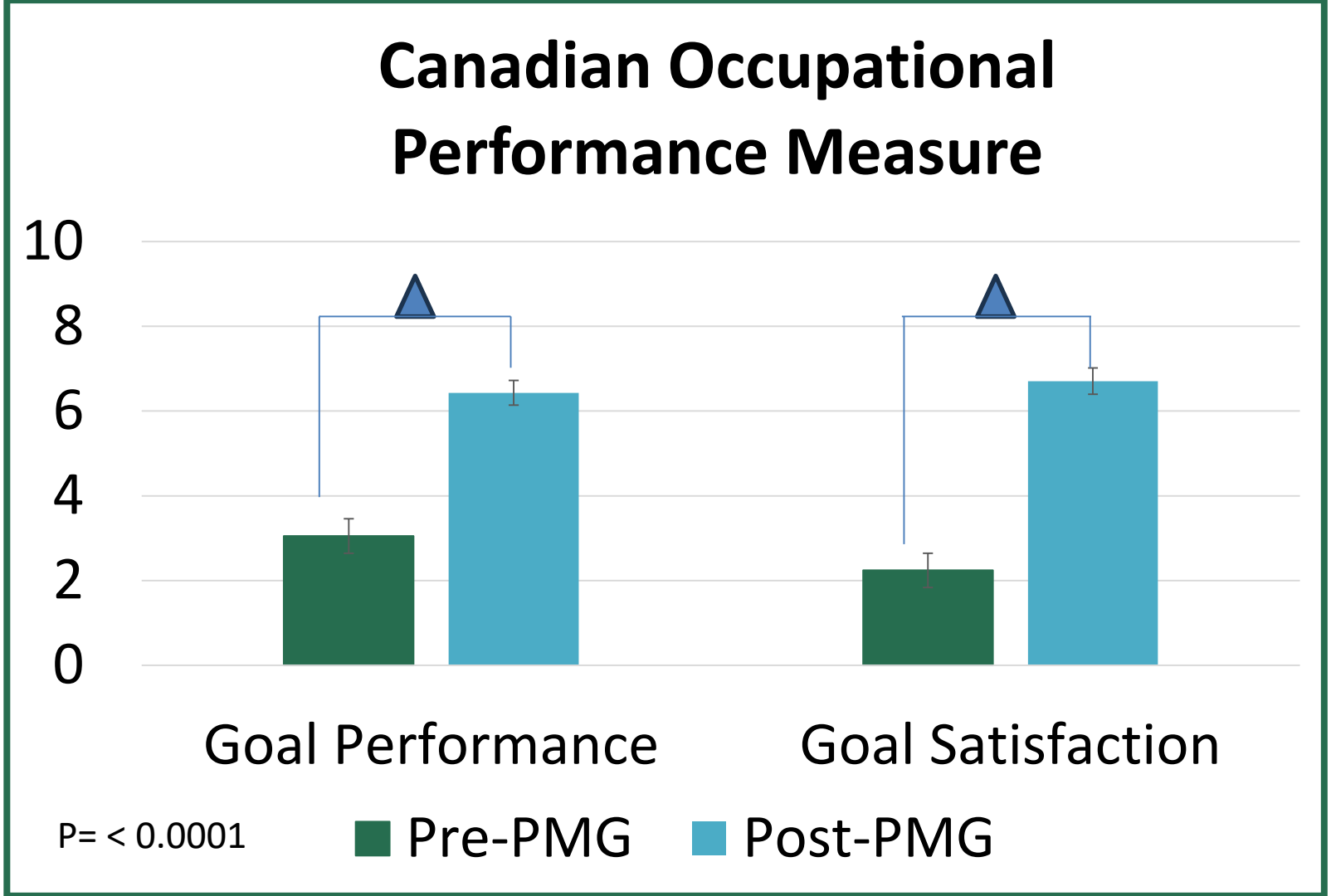
- Quantitative analysis involved repeated measures ANOVA, paired t-tests, and exploratory analysis with mixed-effects modeling.
  - Compared T1 and T2
  - Data imputation completed with T3 due to low numbers
  - Insufficient numbers for meaningful control group
- Qualitative exit interview with each participant post-PMG analyzed using constant comparative analysis

Demographics

- 44 participants were included in the study
- Mean age: 48.8 years (Standard Deviation (SD): 13.0)
- Sex: 24 (55%) were female.
- Diagnosis: 19 (44%) had stroke, acquired brain injury or cerebral palsy, 15 (34%) had a spinal cord injury, 5 (11%) had multiple sclerosis and 5 (11%) were classified as “other diagnosis”
- Mean length of time for pain: 4.8 years (SD: 5.4)
- More than half (56%) of participants attended 8-9 sessions

Paired t-tests comparing T1 and T2

Measure	T1 mean	Relation to pain now	T2 Mean	Relation to pain now	Mean Change	p-value	Reliable change
PCS Raw	26.4 (11.7)	0.43 (0.011)	20.1 (12.6)	0.56 (0.0007)	6.7 (9.3)	0.0004	-3.96
CPAQ	48.1 (16.2)	-0.20 (0.25)	57.6 (13.9)	-0.56 (0.0008)	-9.0 (12.6)	0.0003	4.10
COPM Performance	2.8 (1.6)	0.04 (0.84)	6.4 (1.6)	0.07 (0.73)	-3.4 (2.0)	<0.0001	9.24
COPM Satisfaction	2.1 (1.6)	0.11 (0.56)	6.7 (2.3)	0.05 (0.80)	-4.5 (2.1)	<0.0001	11.86
SF 36 total	36.0 (14.2)	-0.06 (0.73)	44.5 (15.3)	-0.56 (0.0007)	8.2 (14.1)	0.0022	3.34
Pain Now	5.4 (2.0)		5.4 (2.1)		0.12 (1.9)	0.72	0.37
Most Pain	8.0 (1.4)		7.4 (2.0)		0.62 (2.3)	0.1	1.50
Least Pain	3.4 (2.0)		3.3 (2.3)		0.14 (1.6)	0.63	0.49


Canadian Occupational Performance Measure
10
8
6
4
2
0
Goal Performance
Goal Satisfaction
P= < 0.0001
Pre-PMG
Post-PMG

Quantitative results summary

- Participants showed statistically significant positive change on measures of:
  - Pain catastrophizing (PCS)
  - Pain acceptance (CPAQ)
  - Quality of life (SF-36)
  - Goal performance (COPM)
  - Goal satisfaction (COPM)

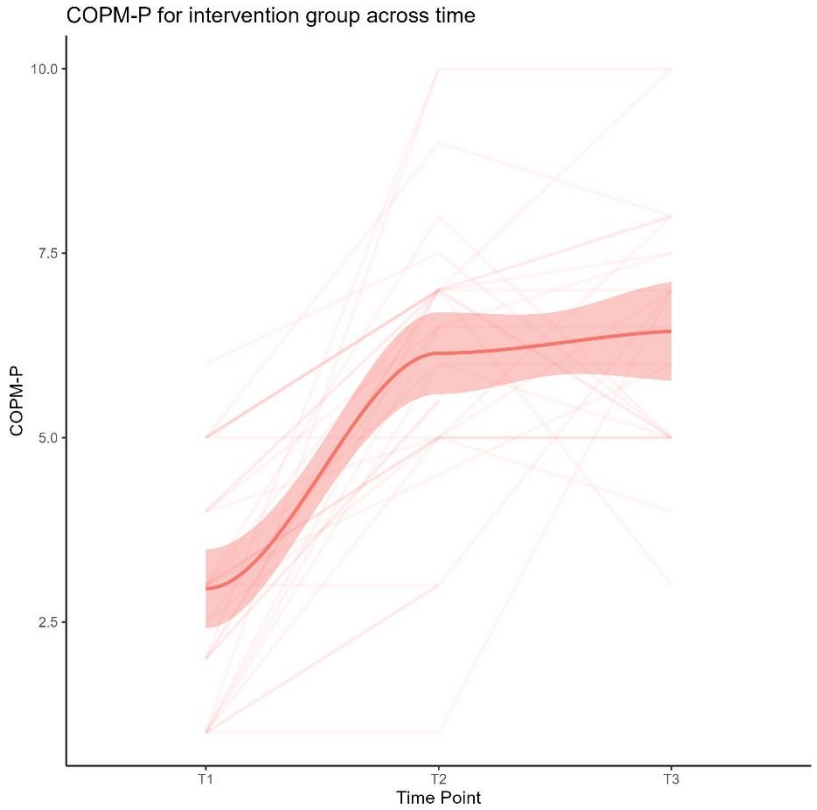
- No significant change in pain intensity on Numeric Pain Rating scale, as hypothesized. The PMG does not target pain intensity.

Descriptive analysis

- Data imputation was used to compensate for the reduced data set at T3
- These spaghetti plots show trends in the data
- Clients made gains from T1 to T2 and then maintained them to T3, indicating lasting change

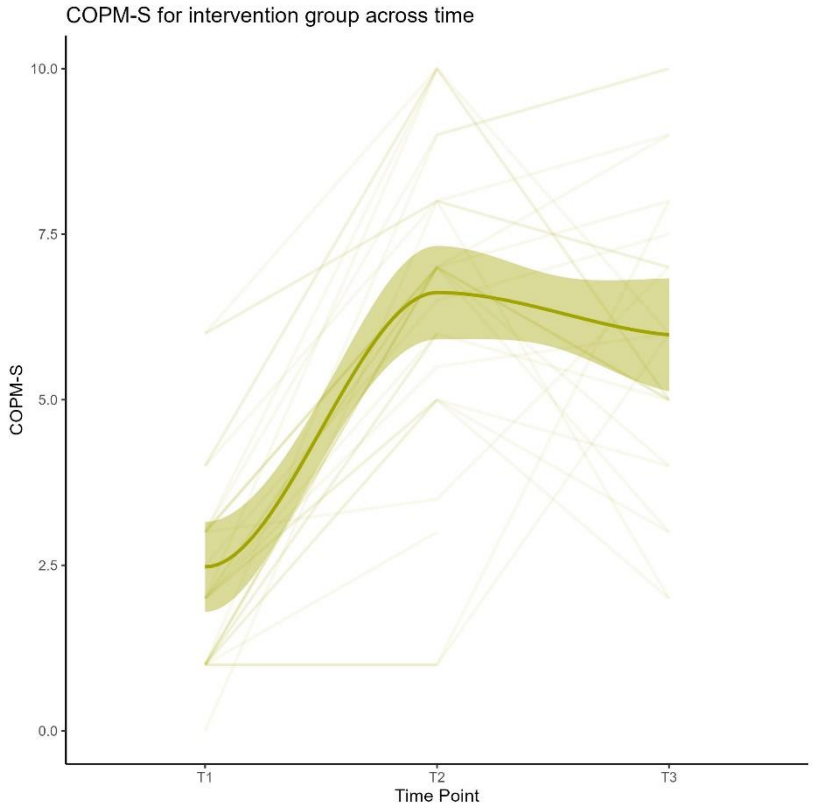
COPM - Performance

Rating of how well you can do a chosen activity



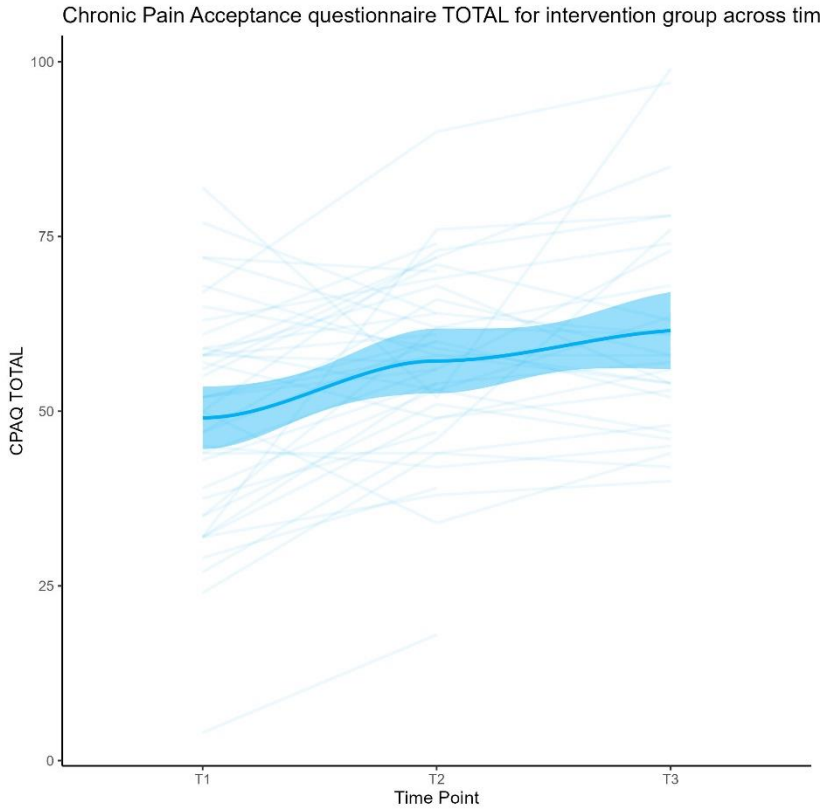
COPM - Satisfaction

Rating of satisfaction with how you perform a chosen activity



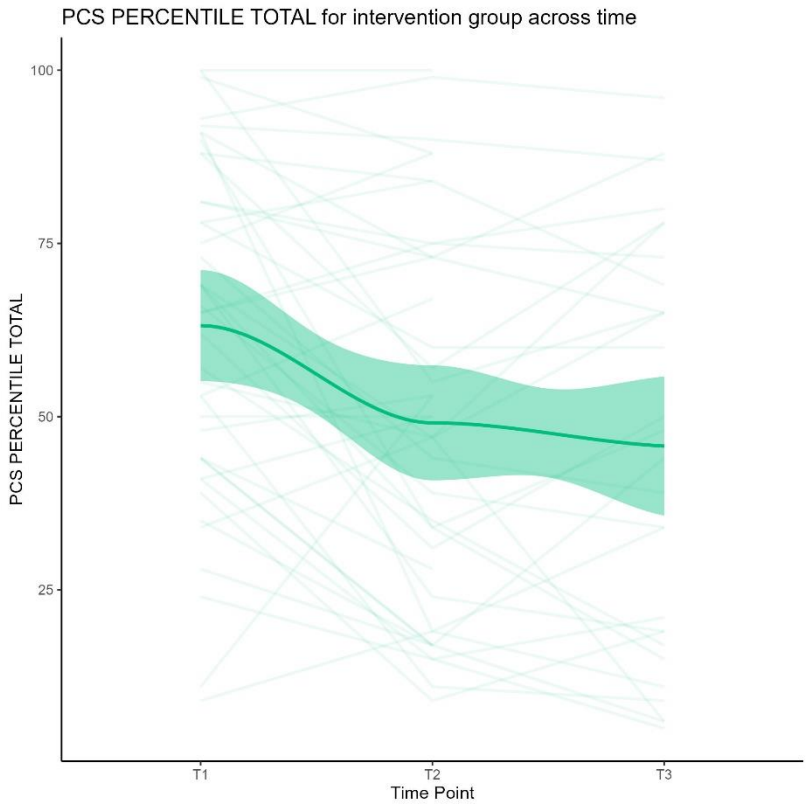
CPAQ – Total Score

Rating of acceptance of chronic pain



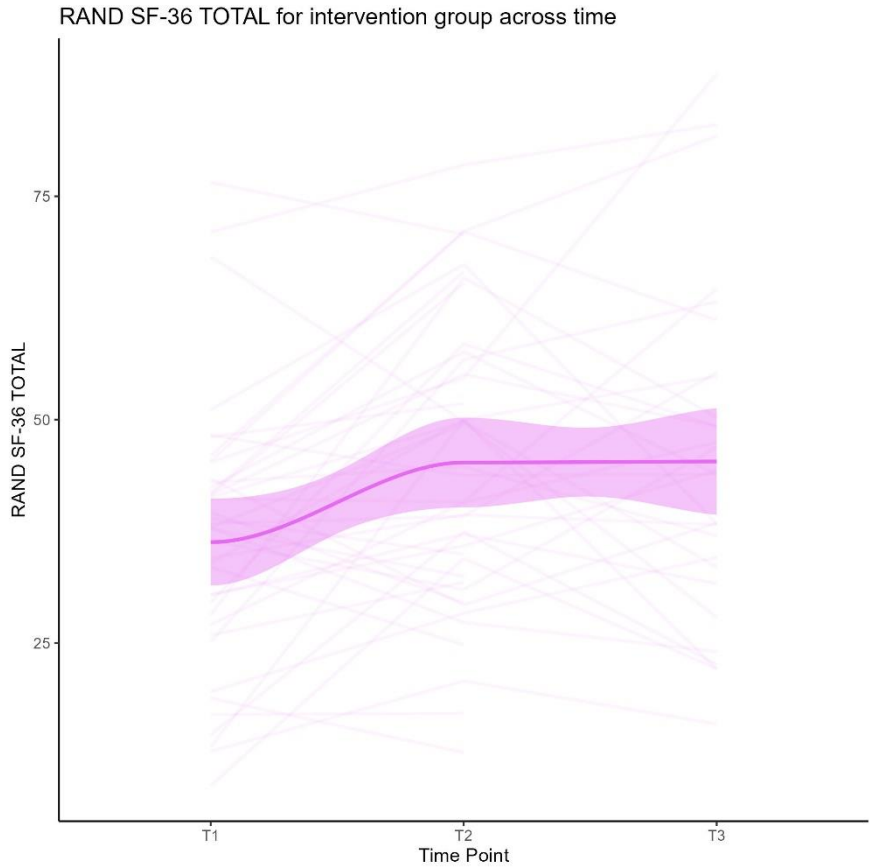
PCS – Total Score

Rating of pain catastrophizing: having distressing thoughts about the pain



SF-36 Total Score

Rating of health-related quality of life



Association Analysis

Linear regression models looked at the association of various outcomes' change from T1 to T2, with potential risk factors (**age, gender, diagnosis, years of pain, number of sessions attended**):

- No associations with gender, years of pain or number of group sessions attended
- Every 1 decade of increase in **age** was significantly associated with a 3.1 point decrease in the change in CPAQ total (95%CI: -5.3, -0.9)

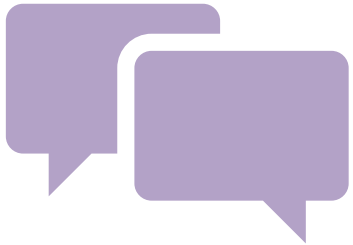
  → **Older participants** showed smaller gains regarding acceptance of pain

- There is no significant difference in outcomes for ABI clients compared to the other diagnoses

Qualitative results summary

Themes:

- Pros and cons of the group format
- Importance of peer dynamics
- Applying group content to daily life and goals



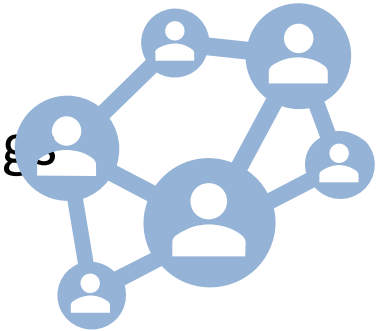
Pros and cons of PMG format

- PMG format well received (especially workbooks, metaphors and language used to describe pain experience).
- Participants provided insights about potential barriers to consider in future - such as travel and time of day.

- *“I liked reflecting back on last week. I liked the movement break and the option to step out if preferred. Enjoyed videos. Facilitators worked well together.”*
- *“I don't have time to work on the things from the group. I work full time, I go home, cook, clean, and I keep it all in. I need time to do the strategies and I don't have time.”*

Importance of peer dynamics

- Peer dynamics were highly valued
- Being able to relate to others promoted feelings of self-worth and reduced social isolation



- *“I liked speaking in small groups because sometimes I feel isolated, so it was great to find others who could relate. There is a sense of comfort in sharing tips with others and giving advice. Almost like a family feeling.”*

Applying group content to daily life and goals

- Participants often described applying the strategies and language they learned in the group to their goals and everyday lives.

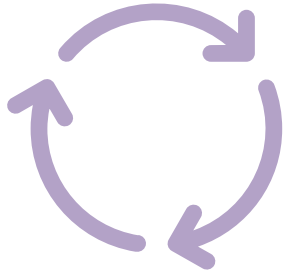
- *“I decreased my pain medication use […] and now I'm using strategies from the group. I need less meds.”*
- *“It gave me a lot of things to use… I'm using coping thoughts throughout my day.”*

Limitations

- Delay in analyzing the data due to loss of key personnel, pandemic disruptions
- Lack of control group
- Lack of data at time 3

Conclusions

- The PMG may promote meaningful change for people with neurological diagnoses and pain in the domains of pain catastrophizing, pain acceptance, quality of life, goal performance and satisfaction.
- Consider future research:
  - Comparing the PMG to a virtual version
  - Comparing PMG to a control group
  - Longitudinal follow up to explore sustainability over time



PRACTICE TIPS FOR PAIN AND ABI

General approach

- Always ask about pain
  - Ask about functional impact of pain: How does pain affect what you want to do or need to do?
- Acknowledge, validate and be curious
  - Motivational interviewing techniques help
- Practice, Practice, Practice Strategies
  - Neuroplastic changes take time
- Adapt Strategies for cognitive impairments

(Mason & Butler, 2010; Institute for Healthcare Communication, 2014)

Essential pain coping strategies

1. Learn about pain science
2. Take breaks from the pain
3. Calm and soothe the nervous system
4. Gently engage with pain

Strategies for Learning about Pain Science

Pain education decreases fear and increases function

Helps make sense of confusing symptoms

For example:

- Explain how pain works in the nervous system – use visual aids
- Explore brain regions involved in pain experience and connect to brain injury
- Differentiate between “hurt” and “harm”
- Provide evidence-based online resources such as www.poweroverpain.ca and www.tamethebeast.org

(Moseley, Nicholas, & Hodges, 2004)

Brain areas involved in pain processing

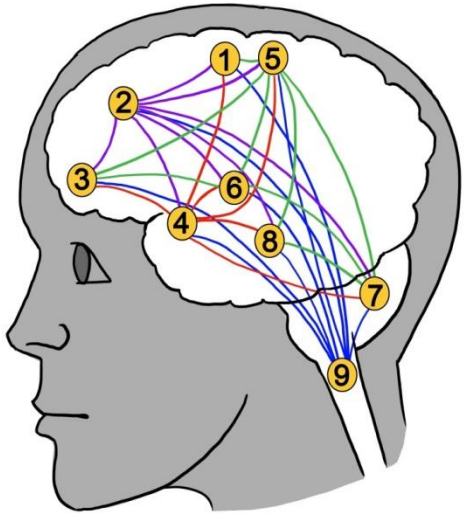


Image by Bronwen Moore, © UHN 2024

(Butler & Moseley, 2014)

	Area	Major Function
1	Premotor/motor cortex	Organize and prepare movements
2	Cingulate cortex	Concentration, focusing
3	Prefrontal cortex	Problem solving, memory
4	Amygdala	Fear, anxiety, anticipation
5	Sensory cortex	“Virtual body”
6	Hypothalamus/ thalamus	Stress response, autonomic regulation
7	Cerebellum	Movement, coordination
8	Hippocampus	Memory

Strategies that let you Take a break from pain:

Provide **relief** from pain **for a little while**.

Allow you to start practicing other skills for the long term.

For example:

- Distraction
- Medication
- Hot bath
- Manual therapies like massage and acupuncture
- Rest
- Ice or heat packs
- Self-massage

3. Cai-Duarte, B., Kircher, C., Moore, B., & Sheffe, S. (2018). Changing your pain pathways: Ways to cope with pain in daily life

The power of distraction

Image by Bronwen Moore, © UHN 2024

Strategies that let you Calm the nervous system:

Send **safety signals** into the nervous system to **counter the danger alarm of pain**.

Allow your nervous system to be in its parasympathetic state, which feels calm or neutral.

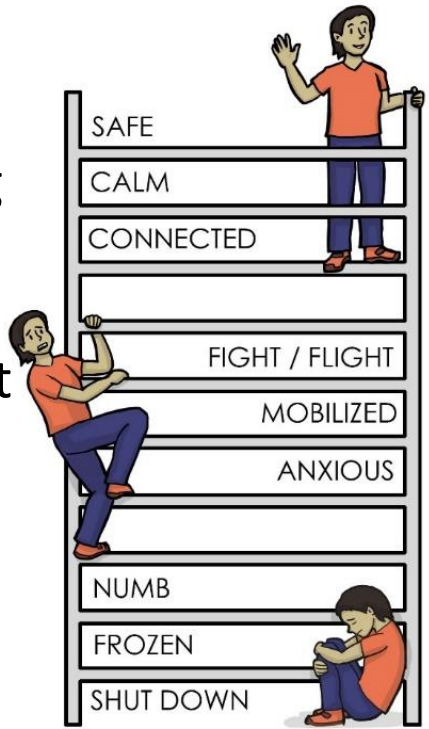
For example:

- Social connection
- Sleep strategies
- Deep breathing
- Gentle stretching or movement
- Guided relaxations
- Meditation
- Self-compassion
- Connection with nature
- Enjoyable hobbies
- Creative activities

3. Cai-Duarte, B., Kircher, C., Moore, B., & Sheffe, S. (2018). Changing your pain pathways: Ways to cope with pain in daily life

Be aware of trauma

- **Trauma Informed Practice (TIP):** reduces harm and re-traumatization for those living with effects of trauma
- Assume everyone could have trauma
- Create safe environment and promote trust
- Support client's autonomy and sense of control
- Teach strategies such as Window of Tolerance
- Connection, compassion and contribution are keys to post-traumatic thriving



Adapted from *The Polyvagal Theory in Therapy* by Deb Dana

Image by Bronwen Moore, © UHN 2024

Davies, 2023; O'Hanlon, 2022

Strategies that let you Gently engage with pain:

Gradually **build exposure and tolerance** to uncomfortable experiences **in ways that feel safe** (including sensations, emotions, and thoughts).

Ways to be present with pain that don't overwhelm.

For example:

- Graded/gradual physical activity
- Psychotherapy (e.g., ACT/CBT/DBT)
- Pacing strategies (balance activity & rest)
- Adapting activities
- Flare up planning and prevention

3. Cai-Duarte, B., Kircher, C., Moore, B., & Sheffe, S. (2018). Changing your pain pathways: Ways to cope with pain in daily life

Fear and avoidance of movement

(Mann, LeFort & VanDenKerkhot, 2013; Wittmer, Stannos, Bertoch,& Gaffron, 2014)

Nerves that fire apart, wire apart

- Help create situations where pain is absent so brain unlearns associations:
  - Gentle activity
  - Pacing
  - Novel situations

- Persisting with daily activities is one of the most powerful ways to improve life with pain

(Molton et al., 2014; Abdallah & Geha, 2017)

“I realized that my life could go on, despite the pain. I learned that it was not all “outside my control”. I learned that I had the power to change the way I thought about pain and reacted to pain. …Although I can’t always make the pain go away, there are things I can do to make it better, to make it easier for myself.”

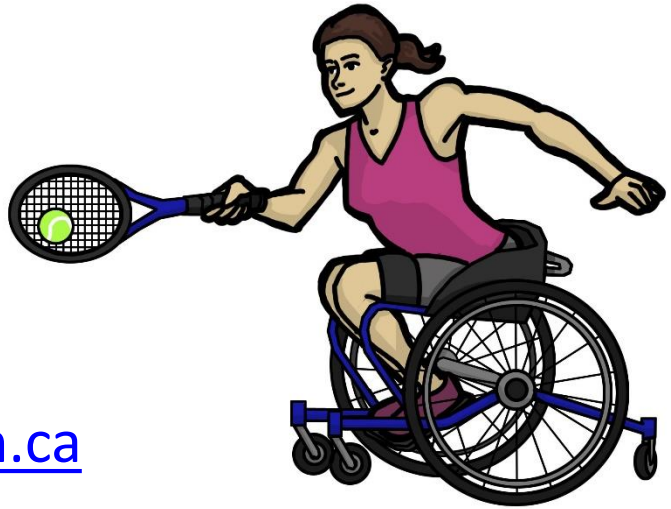
- LEAP Client

In Conclusion

- Pain is common after brain injury
- Self-management education can help
- The Pain Management Group shows promise as a way to adapt self-management for clients with brain injury
- *Note: LEAP Service accepts internal referrals from UHN Brain and Spine program only*

Thank you!

In memory of Debbie Hebert



Questions? LEAP@uhn.ca

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