Care of Persons with Dementia in their Environments (COPE)

Implementing an evidence-based program in Australia – reflections and learnings

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COPE project team

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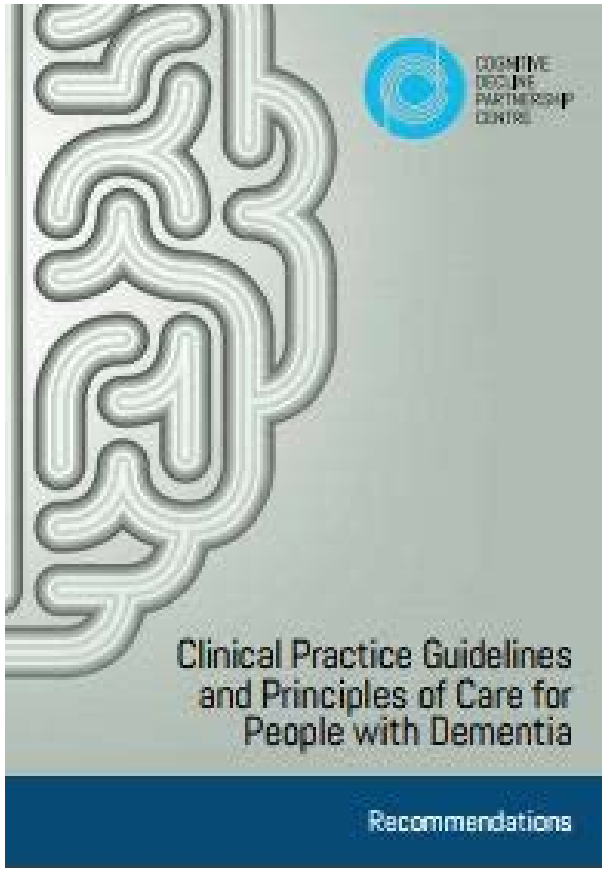
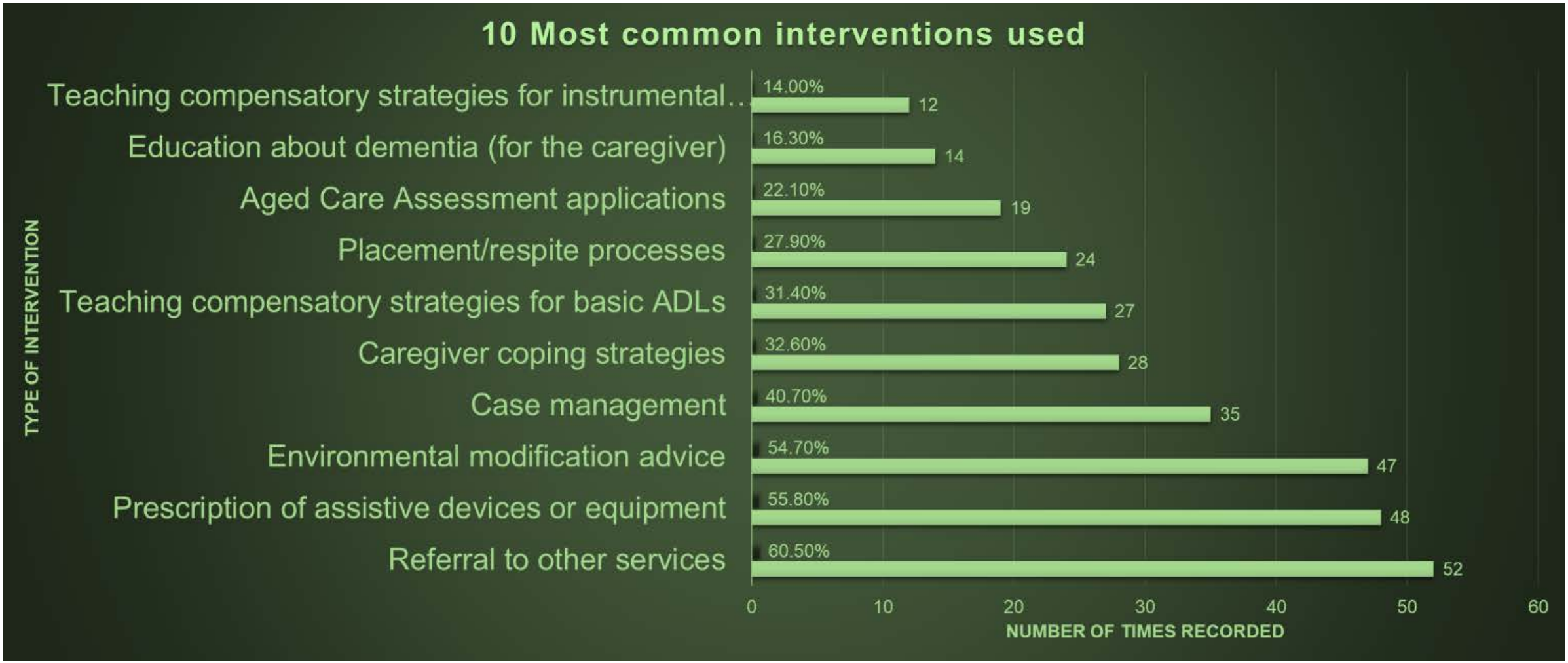
Evidence shows:

- People with dementia living in the community should be offered occupational therapy interventions: include environmental assessment and modification; prescription of AT and tailored intervention to promote ADL (via problem solving, task simplification and education and skills training for carers)

- Where the person with dementia and carer are having difficulty with changed behaviours, intervention should involve: carer skills training; activity planning; environmental modification and problem solving



What is the Evidence-Practice Gap?



Rahja et al, in press, Australian Occupational Therapy Journal

Internationally…

- WHO Global Action Plan calls for implementation of EB interventions that enhance function and capability in people with dementia
- COTiD program (Netherlands)
- Environmental Skill Building Program (renamed Skills2Care) (US)
- Concurrent implementation of COPE in US
- Existing work highlights issues around modification of program (shortening), confidence, fidelity, funding and referrals
- Australia’s health and aged care system is different

A Biobehavioral Home-Based Intervention and the Well-being of Patients With Dementia and Their Caregivers

The COPE Randomized Trial

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Context Optimal treatment to postpone functional decline in patients with dementia is not established.

Objective To test a nonpharmacologic intervention realigning environmental demands with patient capabilities.

Design, Setting, and Participants Prospective 2-group randomized trial (Care of Persons with Dementia in their Environments [COPE]) involving patients with dementia and family caregivers (community-living dyads) recruited from March 2006 through June 2008 in Pennsylvania.

Interventions Up to 12 home or telephone contacts over 4 months by health professionals who assessed patient capabilities and deficits; obtained blood and urine samples; and trained families in home safety, simplifying tasks, and stress reduction. Control group caregivers received 3 telephone calls and educational materials.

Main Outcome Measures Functional dependence, quality of life, frequency of agitated behaviors, and engagement for patients and well-being, confidence using activities, and perceived benefits for caregivers at 4 months.

Results Of 284 dyads screened, 270 (95%) were eligible and 237 (88%) randomized. Data were collected from 209 dyads (88%) at 4 months and 173 (73%) at 9 months. At 4 months, compared with controls, COPE patients had less functional dependence (adjusted mean difference, 0.24; 95% CI, 0.03-0.44; $P=.02$; Cohen $d=0.21$) and less dependence in instrumental activities of daily living (adjusted mean difference, 0.32; 95% CI, 0.09-0.55; $P=.007$; Cohen $d=0.43$), measured by a 15-item scale modeled after the Functional Independence Measure; COPE patients also had improved engagement (adjusted mean difference, 0.12; 95% CI, 0.07-0.22; $P=.03$; Cohen $d=0.26$), measured by a 5-item scale. COPE caregivers improved in their well-being (adjusted mean difference in Perceived Change Index, 0.22; 95% CI, 0.08-0.36; $P=.002$; Cohen $d=0.30$) and confidence using activities (adjusted mean difference, 0.81; 95% CI, 0.30-1.32; $P=.002$; Cohen $d=0.54$), measured by a 5-item scale. By 4 months, 64 COPE dyads (62.7%) vs 48 control group dyads (44.9%) eliminated 1 or more caregiver-identified problems ($\chi^2_1=6.72$, $P=.01$).

Conclusion Among community-living dyads, a nonpharmacologic biobehavioral environmental intervention compared with control resulted in better outcomes for COPE dyads at 4 months. Although no group differences were observed at 9 months for patients, COPE caregivers perceived greater benefits.

Among the more than 5 million dementia patients in the United States, most live at home, cared for by family members.[1] Functional decline, a core disease feature, represents a risk factor for poor quality of life, high health care costs, institutionalization, and mortality.[2-4] With disease progression, families increasingly provide hands-on physical assistance with activities of daily living (ADLs) and instrumental ADLs (IADLs). This often results in heightened caregiver distress, a risk factor for patient nursing home placement.[5]

Few large randomized trials evaluate treatments for supporting physical function of patients with dementia. Trials of antidementia medications show few if any benefits for physical function or caregiver burden and have substantial adverse effects.[6-8] In 1 study, twice-yearly comprehensive care planning in memory clinics showed no additional positive effects on functional

A COPE RANDOMIZED TRIAL - RESULTS AT 4 MONTHS

COPE PATIENTS HAD

Less functional dependence
Less dependence in instrumental activities of daily living
Improved engagement

CAREGIVERS

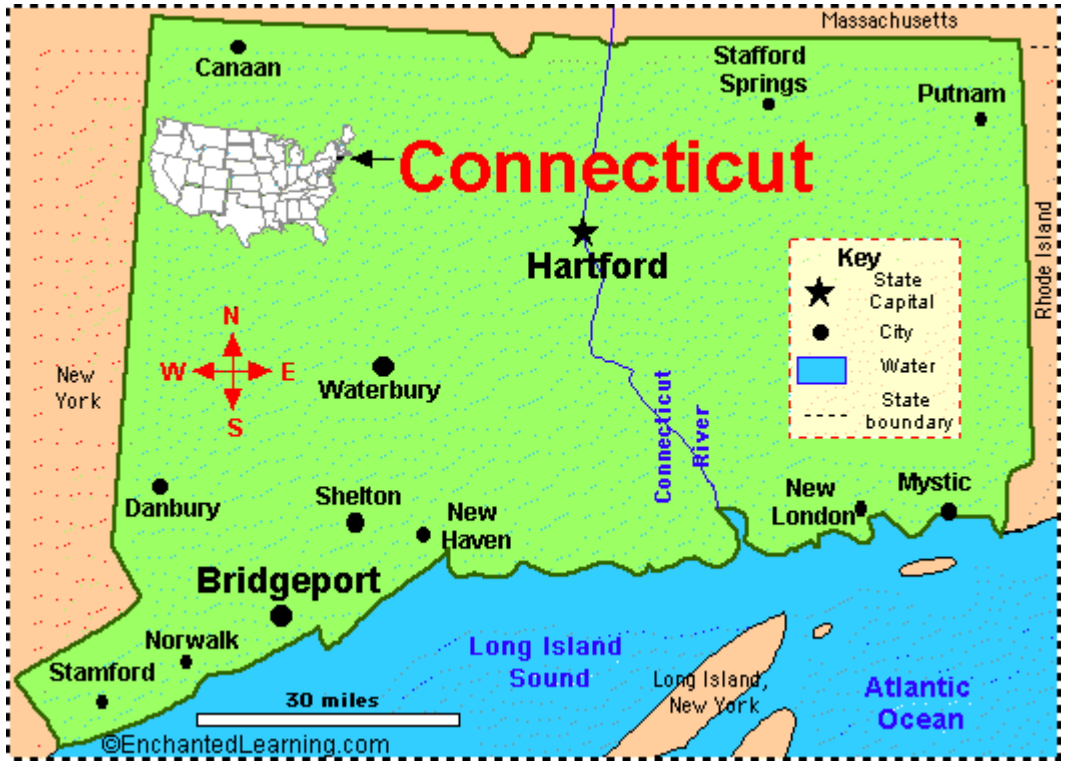
Improved in their well-being and confidence using activities.

62.7% COPE DYADS VS 44.9% CONTROL GROUP DYADS ELIMINATED 1 OR MORE CAREGIVER-IDENTIFIED PROBLEMS

Second trial in US, just completed

- Fortinsky, Gitlin, Peirsol
- Publicly funded home-care program, Connecticut
- Improved
  - Resolution of challenges
  - Confidence level managing challenges
  - Reduced level of carer upset

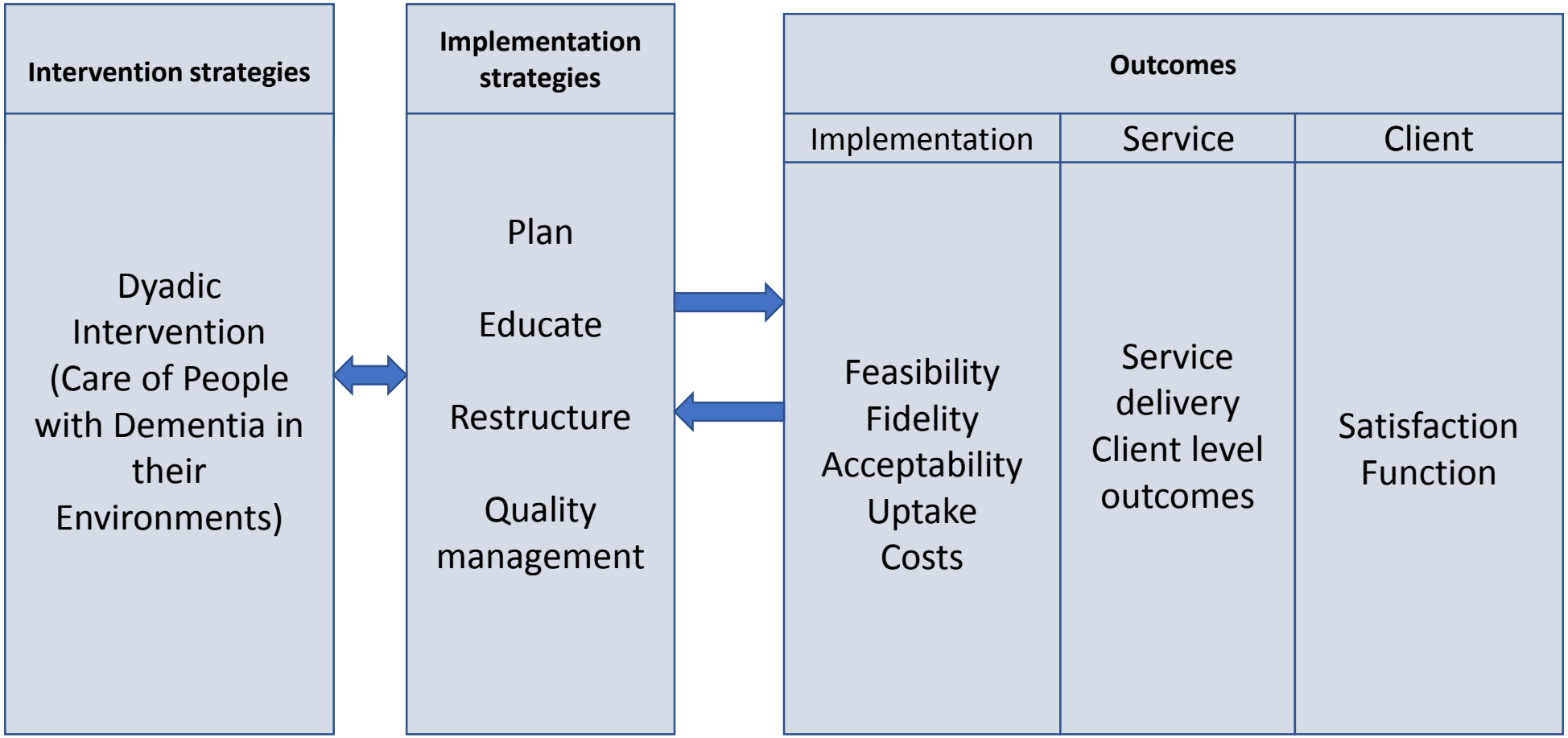
(complete results due early 2019)



Who are our partners?

- From SA and NSW
- Total of 17 organisations/providers
- Government health services
- Non government organisations (aged care providers)
- Private practitioners

Implementation model



Model based on Proctor 2009. Implementation strategies as per Powell 2013

Implementation strategies		Description
Plan	Gather info	• Meetings • Interviews
	Develop relationships	• Identify staff - training, implementation
Educate	Develop materials	• Adapted manual for practice setting
	Educate	• Training workshops for nurses and occupational therapists • Follow-up newsletters, coaching calls
	Influence stakeholders	• Marketing plan
Restructure		• Create new expectations – multiple visits, intervention not assessment • COPE teams
Quality management		• Coaching calls • Fidelity checks • Reminders • Steering committee

Results – training was very successful

- Attendees reported high levels of knowledge acquisition and skill development

- “It was extremely engaging, the time went really quickly and made me feel very confident to be able to apply COPE in practice. This has been the best training I have attended for a really long time!”
- “I am very excited about the COPE programme and feel it is so practical, has a lot to offer carers and people with dementia and naturally linked to OT principles”.

Current status

17 Organisations

- Health 6
- Aged care 5
- Private 6

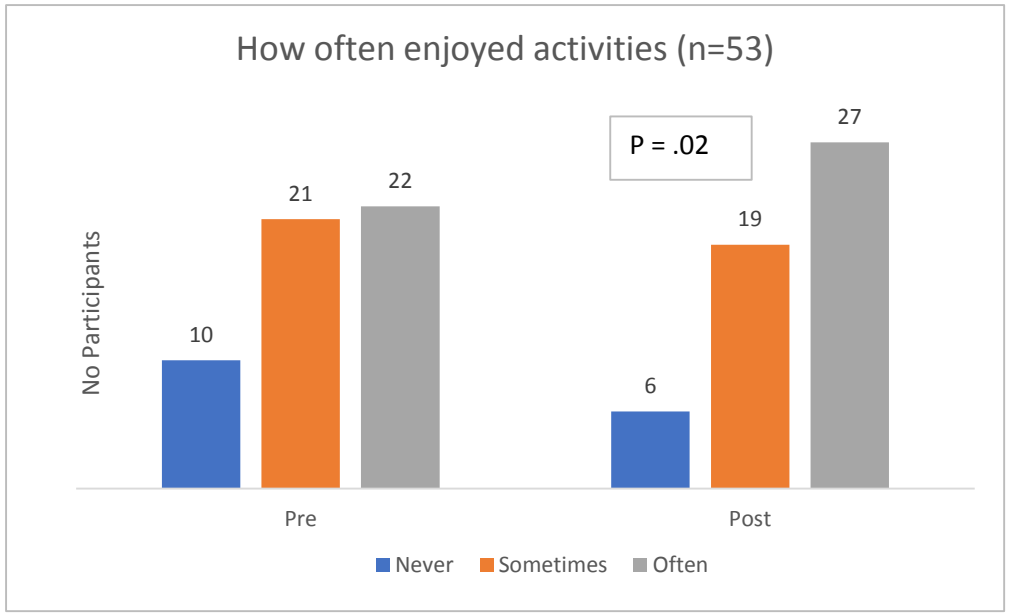
Training

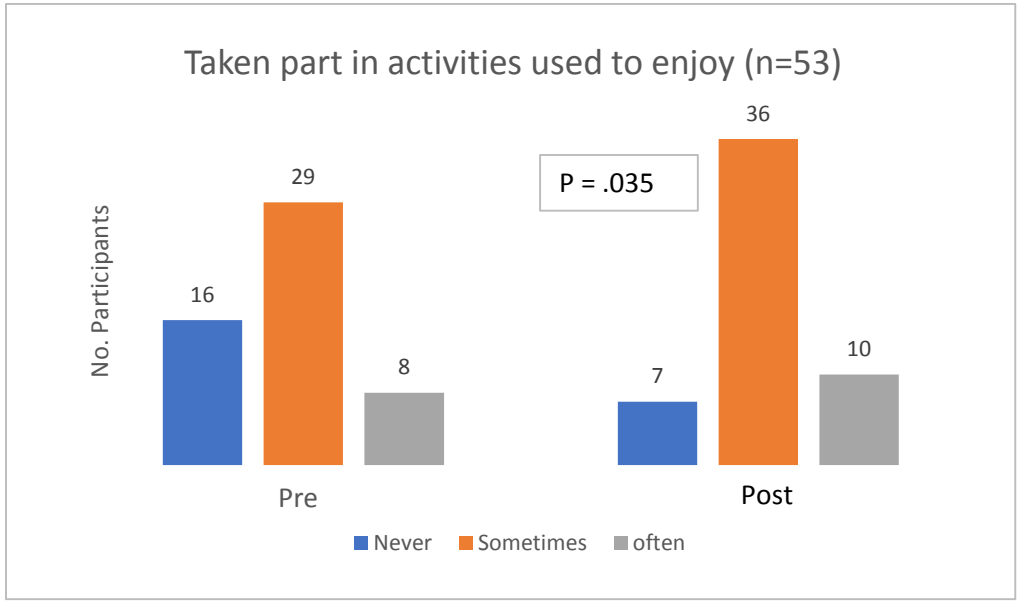
- O T 38 (w = 9)
- Nurse 17 (w = 6)

COPE Programs

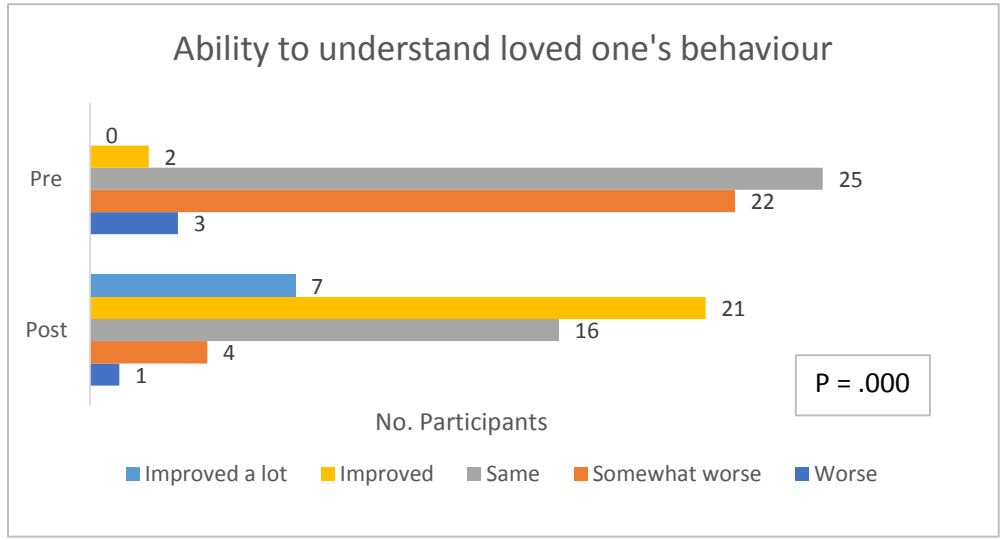
- Programs started 88
- Completed to date 60 (10 drop out – ill health, hospital)

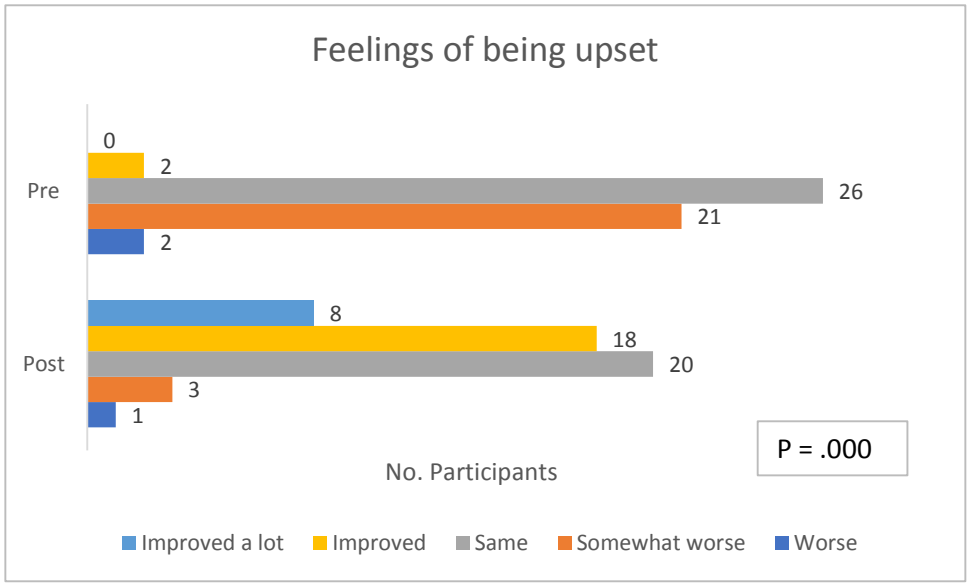
Activity engagement (n=53 included to date)

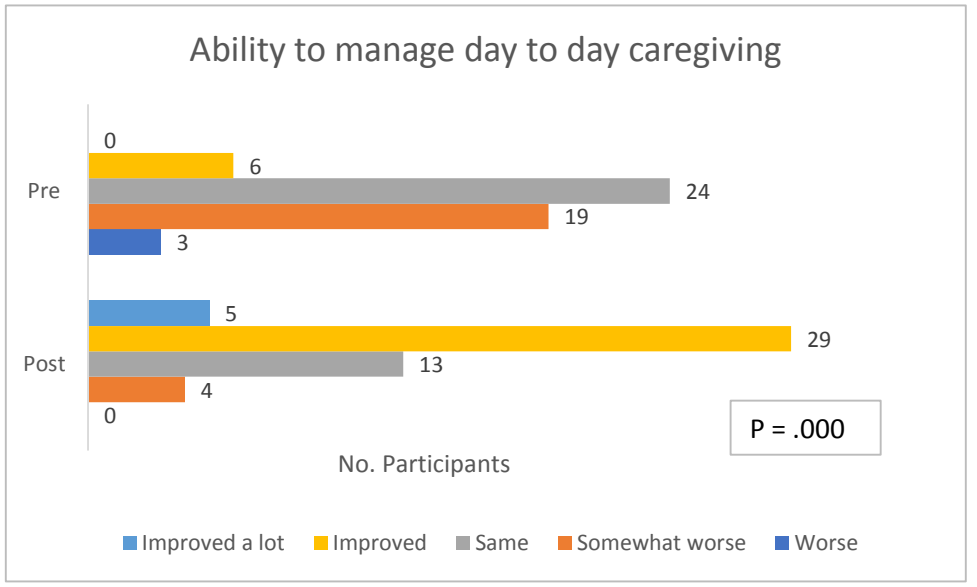




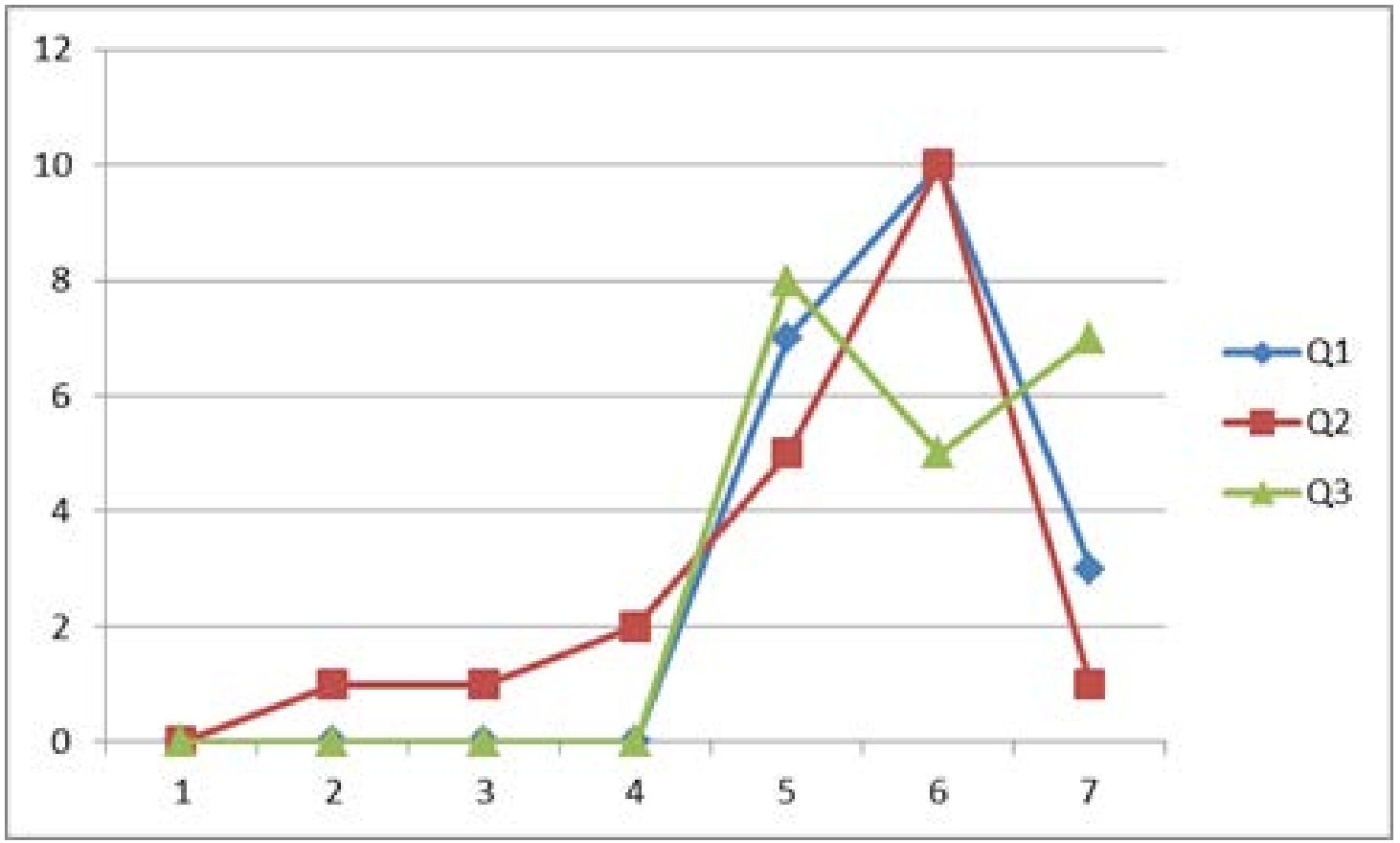
Perceived change



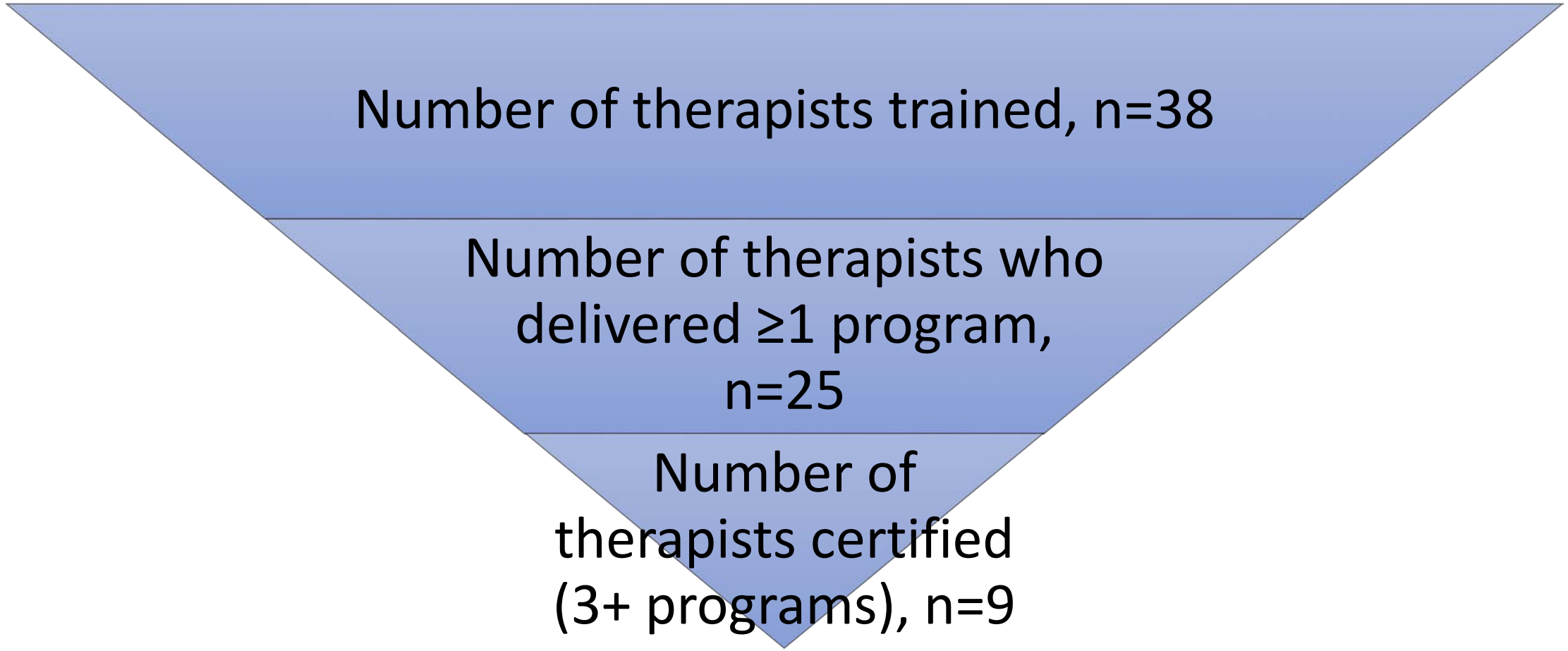




Intentions to implement the program were good



But implementation is hard… and it takes time



Some preliminary reflections on identified challenges and what we've achieved

Enablers

- Knowledge
- Skills
- Beliefs about capabilities
- Optimism
- Beliefs about consequences
- Social influences

Challenges & Opportunities

- Professional Role and Identity
- Still… Beliefs about capabilities
- Reinforcement
- Intentions (great delays in commencing)
- Environmental context (resources, organisational culture)
- Behavioural regulation (breaking habit and action planning)

According to TDF Model

Aiming high

- Organisational change
- A ‘home’ for professional training and support
- Marketing skills in consumer directed care environment
- Targeted action outcomes for consumers, interventionists and organisations
- Policy – fit, access and reach

Acknowledgments

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- Partner organisations
- Investigators
  - Lindy Clemson, Kate Laver, Yun-Hee Jeon, Laura Gitlin, Tracy Comans, Lee-Fay Low, Maria Crotty, Susan Kurrle, Justin Scanlan, Jennifer Culph, Miia Rahja, Sally Day and Monica Cations