Rehabilitation and Dementia

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NHMRC Boosting Dementia Research Leadership Development Fellow
Continuum of AD

International Research priorities

Biomedical model of dementia
Psychosocial conceptions of dementia

Three of topics of significant importance to people with dementia

1. That we have human right to a more ethical pathway of care

2. Being treated with the same human rights as everyone else, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities

3. That research does not only focus on a cure, but on our pre and post-diagnostic care, and on pre and post vention including rehabilitation.
71. Promote community-based rehabilitation as an effective strategy to enable and support people with dementia in preserving their autonomy and rights and ensuring that the person with dementia remains at the centre of all discussions on diagnosis, treatment and care.
Continuum of AD

Rehabilitation - definition

"a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments" (WHO, 2011)
Aims of rehabilitation (WHO)

- prevention of the loss of function
- slowing the rate of loss of function
- improvement or restoration of function
- compensation for lost function
- maintenance of current function
Interventions for cognition
Physical exercise
Physical exercise for cognition in dementia

Exercise for Quality of Life in dementia


<table>
<thead>
<tr>
<th>Study or Subgroup</th>
<th>Exercise</th>
<th>Control</th>
<th>Std. Mean Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Total</td>
</tr>
<tr>
<td>Aguiar et al 2014</td>
<td>34.6</td>
<td>4.1</td>
<td>22</td>
</tr>
<tr>
<td>Hoffman et al 2015</td>
<td>0.92</td>
<td>0.11</td>
<td>107</td>
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<tr>
<td>Lowery et al 2013</td>
<td>104</td>
<td>10</td>
<td>64</td>
</tr>
<tr>
<td>Suttanon et al 2012</td>
<td>25.5</td>
<td>4.4</td>
<td>19</td>
</tr>
<tr>
<td>Telenius et al 2015</td>
<td>17.1</td>
<td>7</td>
<td>82</td>
</tr>
<tr>
<td><strong>Total (95% CI)</strong></td>
<td>294</td>
<td></td>
<td>280</td>
</tr>
</tbody>
</table>

Heterogeneity: Tau² = 0.00; Chi² = 2.03, df = 4 (P = 0.73); I² = 0%
Test for overall effect: Z = 0.72 (P = 0.47)
Combined exercise + cognitive activity for cognition in MCI/dementia

Brain training
Cognitive Training for Any Cognitive Outcome in Healthy Older People

Cognitive training for dementia – no effect on global cognition

Cognitive training for dementia – no impact on function


<table>
<thead>
<tr>
<th>Study or Subgroup</th>
<th>Cognitive training Mean</th>
<th>SD</th>
<th>Total</th>
<th>Control Mean</th>
<th>SD</th>
<th>Total</th>
<th>Weight</th>
<th>Std. Mean Difference IV, Fixed, 95% CI</th>
<th>Std. Mean Difference IV, Fixed, 95% CI</th>
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<tbody>
<tr>
<td>Cahn-Weiner 2003</td>
<td>0.2</td>
<td>7.07</td>
<td>17</td>
<td>0.66</td>
<td>2.81</td>
<td>17</td>
<td>32.4%</td>
<td>0.03 [-0.64, 0.70]</td>
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<tr>
<td>de Vreese 1998</td>
<td>1.33</td>
<td>9.78</td>
<td>9</td>
<td>-1.11</td>
<td>7.52</td>
<td>9</td>
<td>17.0%</td>
<td>0.27 [-0.68, 1.20]</td>
<td></td>
</tr>
<tr>
<td>Galante 2007</td>
<td>-0.6</td>
<td>3.04</td>
<td>7</td>
<td>0.5</td>
<td>1</td>
<td>4</td>
<td>9.4%</td>
<td>-0.38 [-1.64, 0.85]</td>
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<tr>
<td>Loewenstein 2004</td>
<td>-0.6</td>
<td>2.7</td>
<td>25</td>
<td>-0.5</td>
<td>2.41</td>
<td>19</td>
<td>41.2%</td>
<td>-0.04 [-0.63, 0.56]</td>
<td></td>
</tr>
<tr>
<td>Total (95% CI)</td>
<td></td>
<td></td>
<td>58</td>
<td></td>
<td></td>
<td>49</td>
<td>100.0%</td>
<td>0.00 [-0.38, 0.38]</td>
<td></td>
</tr>
</tbody>
</table>

Heterogeneity: Chi² = 7.2, df = 3 (P = 0.07); I² = 0%
Test for overall effect: Z = 0.01 (P = 0.99)
Cognitive Stimulation Therapy

An evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia

The manual for group leaders
Aimee Spector, Lene Thorgrimsen
Bob Woods, Martin Orrell
Published by The Journal for Dementia Care

Making a difference

An evidence-based group programme to offer maintenance cognitive stimulation therapy (CST) to people with dementia

The manual for group leaders
Volume Two
Elisa Aguirre, Aimee Spector, Amy Streater
Juanita Hoe, Bob Woods, Martin Orrell
Published by The Journal of Dementia Care
Cognitive stimulation therapy and cognition

Cognitive rehabilitation

- Principles of rehabilitation flexibly applied to address different types of need at various stages of dementia

  E.g.
  - learn to use email to keep in contact with friends
  - develop strategies to feel confident enough to go out alone
  - be able to cook a meal without getting distracted
  - maintaining the ability to dress herself
  - managing difficulties with swallowing
  - enabling participation in an enjoyable activity

Cognitive rehabilitation

- Compared with active control and treatment as usual CR:
  - ↑ goal performance and satisfaction
  - ↑ subjective memory performance at 6 months
  - fMRI data for a subset: CR ↑ activation during encoding and recognition while undertaking a face-name association task in four brain areas forming part of the network for visual associative learning

Cognitive rehabilitation

SPEECH-LANGUAGE PATHOLOGY

MORE THAN JUST WORDS
Communication difficulties

- Lexical retrieval impairments in PPA
- Studies targeting difficult-to-retrieve items typically report immediate gains
- Gains can be maintained over months to years by some participants who continue with long-term treatment


Figure 1: Number of treatment studies per year by treatment type.
Gait and mobility

Figure 1
Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)

ADLs
- Getting In and Out of Bed
- Eating
- Bathing
- Toileting
- Getting Dressed

IADLs
- Housework
- Grocery Shopping
- Money Management
- Getting Around Inside
- Laundry
- Getting Around Outside
- Medicine
- Preparing Meals
- Going Places Outside of Walking Distance
OT interventions to improve daily function

Dementia Lifestyle Coach

Trevor Crosby

Bobby Redman

Phil Hazell

CI: Kate Swaffer
Henry Brodaty
Sharon Naismith
Nicola Hancock
James O’Loughlin

Funding:
FHS ageing
COMPACT
NHMRC leadership fellowship

Annica Barcenilla-Wong

Michael Fitzpatrick
Prescribed Disengagement®

- “Give up work, give up study, get your end life of affairs in order, and get acquainted with aged care.”
- Suggestion that person should be reducing activities

- Results in people with dementia
  - giving up hope
  - losing self-esteem and self-identity
  - becoming increasingly isolated
  - taking on a ‘sick’ role - developing learned helplessness
  - withdrawing from potentially beneficial activities

## Dementia Lifestyle Coach

### Coach/counsellor
- 14 hours of coaching/counselling
- Structured program
  - Set goals based on values to live well
  - Adjust to diagnosis
  - Manage feelings
  - Stay active physically, mentally, socially

### Peer Supporter
Up to 6 hours of conversation
- Coach/counsellor not present
- Unstructured
  - Emotional support
  - Informational support
  - Practical tips
  - Appraisal support (how the person sees themselves)
Dementia Lifestyle Coach Program

- Diagnosed with any type of dementia in last 12 months, able to participate in program
- Pilot RCT – currently n = 9/20
- Anecdotally achieving behavioural changes
- Results end 2019

- Demonstrating feasibility, refining program
- For larger study:
  - Primary outcome – QOL,
  - Secondary outcomes – cognition, mood, daily function, physical function
Implementation and Evaluation of the Interdisciplinary Home-based Reablement Program (I-HARP)

NHMRC Boosting Dementia Research Grant

CIs
– Yun-Hee Jeon
– Judy Simpson
– Sarah Szanton
– Lee-Fay Low
– Bob Woods
– Richard Norman
– Loren Mowzowski

AlS:
– Lindy Clemson
– Sharon Naismith
– Henry Brodaty
– Sarah Hilmer
– Amanda Miller
– Amberber
– Laura Gitlin

Yun-Hee Jeon
I-HARP Study: A multicentre pragmatic parallel-arm stratified RCT and implementation study

Two overarching aims are:

1) to determine the effectiveness of I-HARP on self-care abilities, independence, mobility, quality of life and depression among people with dementia, their home environmental safety, carer burden and quality of life, and I-HARP cost-effectiveness; and

2) to evaluate the processes, outcomes and influencing factors of the I-HARP implementation to inform consumers, practitioners, service providers and policy makers in their decision making and the use/delivery of the program, as well as for system thinking and changes in the future.
**I-HARP Intervention**

A 4 month, interdisciplinary, model of care integrated with community aged care services, and hospital based community geriatric services, consisting of:

- 12 home visits of 1.5 hours (5-6 x Occupational Therapy (OT), 3-4 x Registered Nurse (RN), plus 2-4 other allied health services), tailored needs.
- Home modification and assistive devices <$1000.
- 3x individual carer support sessions of 1.5 hours

**Interdisciplinary teamwork and coordination**

- Case conference meetings after the initial assessments
- Fortnightly emails and phone conversations
- I-HARP clinicians and family carer in partnership
I-HARP

– https://www.youtube.com/watch?v=EGs2mjH5r4I&feature=youtu.be
Funding from the NHMRC Cognitive Partnership Decline Centre CIs

- Lindy Clemson
- Kate Laver
- Yun-Hee Jeon
- Laura Gitlan
- Tracy Comans
- Lee-Fay Low
- Maria Crotty
- Sue Kurrle
- Justin Scanlan

Research Team
- Jennifer Culph
- Miia Rahja
- Sally Day
- Monica Cations
- Claire Saprgo

Consumer and Industry Advisory Group:
- Danijela Hlis, Glenys Petrie, Jane Thompson, Joan Jackman, John Quinn, Meredith Gresham, Wendy Hudson

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

The COPE Randomized Trial

AMONG THE MORE THAN 5 MILLION DEMENTIA PATIENTS IN THE UNITED STATES, MOST LIVE AT HOME, CARED FOR BY FAMILY MEMBERS. FUNCTIONAL DECLINE, A CORE DISEASE FEATURE, REPRESENTS A RISK FACTOR FOR POOR QUALITY OF LIFE, HIGH HEALTH CARE COSTS, INSTITUTIONALIZATION, AND MORTALITY. WITH DISEASE PROGRESSION, FAMILIES INCREASELY 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 CAREGIVER BURDEN AND HAVE SUBSTANTIAL ADVERSE EFFECTS.

COPE has already been shown to be effective in a large, high quality trial (when delivered according to a research protocol).

COPE – Care of People with Dementia in their Environments

COPE is a dyadic community based bio-behavioral program designed to reduce dependence and improve well-being. Uses multidisciplinary approach:

- Occupational Therapists for problem solving and activity engagement
- Nursing skills for reviewing health needs and providing support for medications, hydration, continence, pain and infection management.

Up to 10 sessions per patient/caregiver dyad in 4 months

Up skilling caregivers

COPE has already been shown to be effective in a large, high quality trial (when delivered according to a research protocol).
Model based on Proctor 2009. Implementation strategies as per Powell 2013
Research questions

– How is COPE adopted, implemented and made sustainable within different community health contexts in Australia?

– What are the costs associated with delivery of COPE and are there changes in resource utilisation of people with dementia before and after intervention? and

– When implemented into existing services, does COPE have similar activity engagement outcomes for the person with dementia and wellbeing outcomes for the carer as when tested in the randomised controlled trial?
2010 • Results of RCT published

2016 • Funding awarded for implementation project within CDPC

2016 • Ethics obtained date, ongoing discussions with partner organisations

2017 • First round training (Adelaide and Sydney)

2017 • Second round training (Adelaide and Sydney)

2018 • Completion of data collection and commence analysis and write-up

Future • Dissemination, plan for ongoing training via master trainers
Number of therapists trained, n=38

Number of therapists who delivered ≥1 program, n=27

Number of therapists certified (n=15)
Fidelity to intervention

Average visit time = 635 minutes (ie 10 hours, 35 minutes)
Fidelity to intervention (n=14)

Was the nurse visit and follow up phone call completed?

- Not sure
- No
- Yes

[Bar chart showing the distribution of responses]
Fidelity to intervention \( (n=14) \)

Content of the intervention

![Graph showing the content of the intervention with bars for Problem 1, Problem 2, Problem 3, and Activity.]
Fidelity to intervention (n=14)

Please rate your perception of how effectively the carer implemented COPE prescription #1

- N/A - not completed
- Very effectively
- Quite effectively
- Somewhat effectively
- Not very effectively
- Not at all effectively
Rehabilitation

Hospital based, or outpatient clinics

Can include
- Physical therapy
- Occupational therapy
- Speech therapy
- Psychiatric rehabilitation
- Other allied health – dieticians, audiologist

Physical goals emphasised, daily function goals as well
Transitional Care

Definition:
- short-term care to optimize functioning and independence after a hospital stay. It is goal-oriented, time limited, therapy focused

Can include:
- nursing support
- personal care
- domestic assistance
- Limited physiotherapy, occupational therapy, social work, speech pathology

Target usually avoiding rehospitalization, disease management

Restorative care

- Definition:
- evidence-based interventions led by allied health workers that allow a person to make a functional gain or improvement after a setback, or in order to avoid a preventable injury
- Time limited
- Target usually daily function

Department of Health, 2015, Living well at home: CHSP good practice guide.
Reablement

- Definition
- time-limited interventions that are targeted towards a person’s specific goal or desired outcome to adapt to some functional loss, or regain confidence and capacity to resume activities.
- Delivered by non-allied health trained staff
- Target usually daily function

Department of Health, 2015, Living well at home: CHSP good practice guide.
Wellness

- Definition
- involves assessment, planning and delivery of supports that build on the strengths, capacity and goals of individuals, and encourage actions that promote a level of independence in daily living tasks, as well as reducing risks to living safely at home.
- Delivered by home care team
- Not time limited

Department of Health, 2015, Living well at home: CHSP good practice guide.
Rehabilitation

Transitional care

Reablement

Wellness approach

Probable amount of improvement

Less
LifeFul


**Funding:** NHMRC Career Development Fellowship, the Centre for Healthy Brain Ageing and The Whiddon Group.
Person centred care and behaviour

**Intervention**

**Leadership support**
- Staff training – focus carers, communication, goal setting, personalised activities, choice and control, incidental exercise

**RAO training** – lifestyle leadership, activities for sense of community, environmental modifications

**RN training** – clinical leadership, BPSD, task analysis

**Procedural changes** – ‘all about me’, goal setting, care plan reviews, handovers

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**Short term change**

**Residents**
- ↑ better relationships
- ↑ tailored activities
- ↑ focus on social life
- ↑ choice & control
- ↑ incidental exercise

**Staff**
- ↑ engagement with residents/families
- ↑ team-work
- ↑ engagement with care planning

**Families**
- ↑ engagement with staff
- ↑ engagement with care planning

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**Long term outcomes**

**Residents**
- ↑ Social care related QOL (ASCOT)
- ↑ physical function
- ↑ mood/social engagement
- ↑ function
- ↓ agitation

**Staff**
- ↑ Person-centred care
- ↑ satisfaction with work

**Families**
- ↑ engagement with staff
- ↑ engagement with care planning
Dedicated Rostering

- Residents only receive personal care from a small number of staff a week
- Rostering in ‘areas’ of 12 to 20 staff
- No changes to staff ratios, budget

Issues?
- Less flexible for staff and management – e.g. holidays, sick leave
- Some areas/residents less desirable than others
- Personality clashes
Role of a focus carer

- Each resident allocated a focus carer
- Focus carers must work minimum # of shifts per week

Role:
- To get to know the resident well and develop a relationship
- To get to know and work with the resident’s family to maximise the resident’s wellbeing
- To take the lead in focusing on the resident’s wellbeing and quality of life
- To act as a spokesperson for the resident’s wellbeing to other staff members
Implementation

– All residents were allocated a focus carer
– 86% of residents had an All About Me completed
– 45% had been focus resident of the week at 12 months

Training attendance
– session 1 – 88%
– session 2 – 62%
– session 3 – 88%
– session 4 – 76%
Table 4. Resident outcomes

| Adult Social Care Outcome Toolkit ASCOT          | N=76 | N=67 | b = -0.03, p = 0.02
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Domain 1 Control</td>
<td>0.79 (0.23, N=76)</td>
<td>0.85 (0.21, N=67)</td>
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<tr>
<td>Domain 2 Personal Hygiene</td>
<td>0.86 (0.14, N=76)</td>
<td>0.88 (0.07, N=67)</td>
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<tr>
<td>Domain 3 Food</td>
<td>0.79 (0.19, N=76)</td>
<td>0.80 (0.18, N=67)</td>
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<tr>
<td>Domain 4 Safety</td>
<td>0.69 (0.10, N=76)</td>
<td>0.72 (0.00, N=67)</td>
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<tr>
<td>Domain 5 Social Participation</td>
<td>0.72 (0.17, N=76)</td>
<td>0.76 (0.15, N=67)</td>
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<tr>
<td>Domain 6 Occupational Engagement</td>
<td>0.79 (0.20, N=76)</td>
<td>0.85 (0.18, N=67)</td>
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<tr>
<td>Domain 7 Accommodation</td>
<td>0.85 (0.05, N=76)</td>
<td>0.86 (0.00, N=67)</td>
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<tr>
<td>Domain 8 Dignity</td>
<td>0.75 (0.12, N=76)</td>
<td>0.78 (0.00, N=67)</td>
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<tr>
<td>ASCOT Total (SCRQoL)</td>
<td>0.84 (0.17, N=76)</td>
<td>0.89 (0.12, N=67)</td>
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<thead>
<tr>
<th>Short Physical Performance Battery (SPPB)</th>
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<tbody>
<tr>
<td>Balance Test Total Score</td>
<td>1.63 (1.05, N=52)</td>
<td>1.81 (1.09, N=36)</td>
</tr>
<tr>
<td>Gait Test Total Score</td>
<td>2.40 (0.95, N=52)</td>
<td>2.64 (0.90, N=36)</td>
</tr>
<tr>
<td>Repeated Chair Stand Score</td>
<td>0.67 (1.06, N=52)</td>
<td>0.81 (1.14, N=36)</td>
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<thead>
<tr>
<th>Social Identification and Satisfaction Subscale (SIS)</th>
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</tr>
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<tbody>
<tr>
<td>Social Identification</td>
<td>4.36 (0.96, N=57)</td>
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<tr>
<td>Satisfaction with Lounge</td>
<td>4.79 (1.52, N=57)</td>
</tr>
<tr>
<td>Satisfaction with Life in the Home</td>
<td>3.67 (0.72, N=57)</td>
</tr>
</tbody>
</table>

| Cornell Depression Total                          | 7.12 (7.91, N=80) | 4.49 (4.30, N=67) |

<table>
<thead>
<tr>
<th>Cohen Mansfield Agitation Inventory (CMAI) Total</th>
<th></th>
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<tbody>
<tr>
<td>N=80</td>
<td>40.94 (14.31, N=80)</td>
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<thead>
<tr>
<th>Disability Assessment for Dementia (DAD) Total</th>
<th></th>
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<tbody>
<tr>
<td>N=80</td>
<td>41.46 (27.45, N=80)</td>
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b = -5.50, p = .04
Example of impact

– Lucia
Doris
Doris
Doris
Thanks to the staff and family at The Whiddon Group
2018 Better Practice Award for Innovation
Aged Care Quality Agency

The Whiddon Group rolled out LifeFul to all 18 of their facilities
Train the trainer 1 has begun implementation
Discussions with 2 others

Many others implementing their own version
Dementia Rehabilitation
Evidence Based Interventions and Clinical Recommendations
Lee-Fay Low
Kate Laver

To be published by Elsevier in 2020

(mock cover)
Possible attitudes towards rehab & dementia

This doesn’t apply to me in my work

Rehab will only work for certain people with dementia

No one is going to fund this

The extra resources aren’t worth it, they are going to deteriorate in the long run
Research gaps (lots)

- How to rehabilitate: communication, social participation, balance and gait, perception
- By type of dementia, level of severity of symptoms
- Cost-benefit
- Involvement of person with dementia and care partners/family in interventions
- Use of technology
- Implementation in developing countries
- Barriers:
  - Ageism, stigma, denial and apathy
  - Attitudes and skills of health care professionals
Wanted: people with dementia and care partners interested in co-designing research on stigma

- What are foundational questions that we need to answer/provide evidence for around stigma?

- Web working group to inform research grant

- Please email me lee-fay.low@sydney.edu.au
“I remember on that day of rage thinking that if I’d been diagnosed with cancer of any kind, at least there would have opened in front of me a trodden path. There would have been specialists, examinations; there would be in short, some machinery in place. I was not in the mood for a response that said, more or less, 'go away and come back in six years'