



WICKING

DEMENTIA RESEARCH
& EDUCATION CENTRE

**Research Increasing
Independence for people
with Dementia in Tasmania
Dr Christine Stirling**

Vision for WDREC

The vision of the Tasmanian Dementia Research and Education Centre is to prepare Tasmania for the increasing numbers of people with dementia.

Mission

**To establish an internationally recognised
centre conducting research into dementia**

Funding

Five year funding has been achieved to establish this Centre with the major funding coming from the JO and JR Wicking Trust. Other funding partners are UTAS (including the School of Nursing and Midwifery), Menzies Research Institute, and DHHS Tasmania

Goals

- **To improve dementia service delivery in Tasmania and to foster evidence based practice**
- **To undertake research into new therapeutic interventions**
- **To build research capacity and provide education and training to the dementia care workforce**
- **To establish a data base of information about people with dementia in Tasmania**

Some Current Projects

1. **Trajectory of Dementia Care**
2. **Dementia Day Centre Respite**
3. **Carers of People with Dementia**
4. **Tasmanian Older Persons Database**
5. **Biological Basis of Dementia**
6. **Drug Discovery for neurodegenerative disorders**

1 Trajectory of Dementia Care Project - Research Investigators

Prof Andrew Robinson, School of Nursing &
Midwifery – Chief Investigator

Prof James Vickers,
School of Medicine

Assoc Prof Paul Turner,
School of Information Systems

Project Aims – Stages 1 and 2

- To scope the information available to people involved with dementia care in Southern Tasmania
- To conduct an information audit on the variety of health care services and settings (e.g. HACC, GPs, residential aged care) as they relate to the management of people with dementia

2 Dementia Respite Project - Research Aims

- To explore how well current services and therapy programs provided by day centres meet the needs of the clients with dementia, memory loss or cognitive deficits.
- To determine the specific issues that inhibit clients with dementia, memory loss or cognitive deficits, from accessing day centres

2 Dementia Respite Project

Focus groups involving (a) carers of people attending day centres and (b) staff of those day centres

Telephone interviews of carers of people who have withdrawn or failed to attend day centres

Audit of day centre activities

Progress

Data collection completed

Analysis is underway

Large amount of very detailed information

Preliminary results indicate little difference between dementia specific and general day centre activities

Results will be published later in 2008

3 Service Utilisation and Wellbeing in Carers of People with Dementia

Project funded by HACCC - DHHS

- How carers seek information about helping services
- Carer usage and satisfaction with such services and
- How those services interact with carer coping/wellbeing.

4 Tasmania Older Persons Database

To develop:

1. A database for use as clinical tool and assist with the service performance reporting requirements in selected RHH wards
2. A framework for obtaining consent of potential research participants to be contacted in relation to future studies
3. A dataset that will facilitate specific clinical research projects using de-identified patient data to determine the functional and cognitive status of patients

Three Stages

Stage 1. Approximately September-October 2008

Consultation with service providers to determine features for construction of an internet-accessible, secure database for recording and accessing information in a number of clinical domains

Stage 2. Trial data entry November 2008 – January 2009

Stage 3. Main trial February 2009 – April 2009

The database will become active for use by selected RHH ward staff for three months for admitted patients.

5 Biological Basis of Dementia

This project involves laboratory investigations of human brain tissue and experimental models to determine the key cellular changes that lead to neurodegeneration in Alzheimer's disease and related dementias

6 Drug Discovery for neurodegenerative disorders

Wicking Centre have developed novel cell culture and other experimental models that replicate key cellular changes of Alzheimer's disease and related conditions. These model systems are being used to determine new therapeutic approaches that target the very earliest stages of the major neurodegenerative conditions.

Future research projects

- Funding from DHHS received to develop & evaluate an innovative self help coping program for dementia care givers (CarersCARE)
- Research underway looking at a palliative care approach to dementia care in residential care settings
- Major funding applications submitted for further research into dementia and palliative care in residential care settings
- Proposed projects in rural ageing and with GPs and dementia care

Education

- TIME – free online modules for health professionals caring for people with dementia
- Regular seminars of interest – e.g Environmental Design
- Summer school for research graduate students
- PhD and Masters students

Contact

Wicking Dementia Research and
Education Centre

Phone 03 62264881 or 03 62264708

e-mail: Gillian.vosper@utas.edu.au



WICKING

DEMENTIA RESEARCH
& EDUCATION CENTRE

Family carers of
people with dementia:
their wellbeing and
usage of support
services

2007-8 HACCC Study

UTAS/RHH were funded by DHHS (HACC) to study local service usage by carers in Tasmania.

20 carers of PWD who utilised HACCC services were studied over 3 months using mixed methodology:

- Quantitative assessments
- Carer journals
- Weekly telephone calls
- Monthly in-depth interview

Investigators

Professor Andrew Robinson (Aged Care Nursing, UTAS)

Prof James Vickers (School of Pathology, UTAS)

Dr Toby Croft (Clinical Neuropsychologist, RHH)

Ms Jean Elder (Project Manager, Nursing, UTAS)

Dr Carolyn Emden (Senior Research Officer)

Ms Gillian Vosper (Research Assistant)

Aims:

Document the cognitive and behavioural issues carers must manage in their role.

Document service amounts & types utilised by carers

Document levels of carer strain

Aims:

Investigate carer satisfaction with services received.

Investigate relationships between carer strain, dementia severity and service use.

People with dementia

Cognition?

Mood and Behaviour?

Everyday functioning?



Suggested Guidelines for Interpretation of DRS-2 AMSS or AEMSS Total Scores

AMSS or AEMSS	%ile range	Clinical Interpretation
18	>99	Above Average (Intact)
17	99	
16	98	
15	95-97	
14	90-94	
13	82-89	Average (Intact)
12	72-81	
11	60-71	
10	41-59	Below Average (Intact)
9	29-40	
8	19-28	Slightly Impaired
7	11-18	
6	6-10	
5	3-5	Moderately Impaired
4	2	
3	1	Severely Impaired
2	<1	

20 cases of mixed dementias
in Hobart community.

All being cared for at home,
with services to support carer.

2 cases

3 cases

15 cases

PWD had very significant cognitive impairments:

75% of PWD had cognitive scores <1st %ile for age
(Mattis Dementia Rating Scales 2)

eg. only 40% of PWD could name the current year and just 25%
could say how a train and a car are similar.

PWD had significant everyday impairments:

Bayer Activities of Daily Living (ADL) scale indicated significant impairment in most PWD including the following:

- 70 % struggled with using household appliances
- 70% had trouble in everyday conversation
- 70% struggled with basic shopping
- 80% were unable to manage their own medications
- 85% had significant difficulty using the telephone,
- 100% of PWD had difficulty coping in any unfamiliar situation.

PWD commonly had Behavioural & Psychological Symptoms of Dementia (BPSD)

Carer's Checklist indicated:

- 10% had been physically aggressive with carer (2 cases)
- 30% of PWD had episodes of shouting
- 40% of PWD sometimes wandered at night
- 50% of PWD had temper outbursts
- 60% of PWD were “restless” and “on the move”
- 60% of PWD showed no concern for their personal hygiene
- 75% of PWD were constantly asking questions of carers
- 100% of PWD were anxious/agitated/frustrated at times.

Carers reported moderate levels of strain on *subjective* (likert) scales:

Carer's Checklist averages:

•Financial strain	2.05
•Physical strain	2.75
•Social strain	3.05
•Emotional strain	3.5

(RATED 1=no burden...3=moderate burden...5= great burden)

In contrast, carers reported poor mental health on *objective* measurement:

Carers were twice as likely as their age peers to have a probable mental health problem (anxiety/depression) on GHQ-30 test.

- GHQ-30 scores above 5 indicate a likely problem:

The average for our carers was **8.35**

<5	= 7 carers
5-10	= 7 carers
11-20	= 4 carers
>20	= 2 carers

Thus 2/3 of our sample had a likely mental health problem



So...

People with dementia (PWD):

- Significantly cognitively impaired (most <1st %ile for age)
- Significantly impaired in everyday living
- Showing significant behavioural and mood symptoms

Carers:

- Report moderate strain on subjective tests....BUT
- Twice the usual incidence of anxiety/depression on objective measurement.
- Carer strain is easily underestimated/understated.

Service usage by Carers

What levels of service usage were typical of this sample of carers?

5 hours per week?

10 hours per week?

15 hours per week?

AIHW Dementia in Australia report 2007-2002 CACP and EACH figures

	CACP hpw	EACH hpw
Personal care	2.4	8.8
Domestic	2.0	2.2
Respite care	4.0	5.0
Social support	2.6	2.5

Amounts of service (hours)

	Average Hrs Per week	Minimum Hrs 12 weeks	Maximum hrs 12 weeks
Practical (12/20)	3	5	125
In-Home Respite (11/20)	4	23	119
Out-Home Respite (14/20)	4	2	136
In and Out Respite (5/20)	8	28	216

How do dementia severity and carer strain relate to service usage?

Are respite and practical services weighted to:

- Carers under the most strain?
- Carers of people with more severe dementia?

How do dementia severity and carer strain relate to service usage?

Much of the published literature indicates carer strain, dementia severity and amount of service use do NOT relate directly to each other.

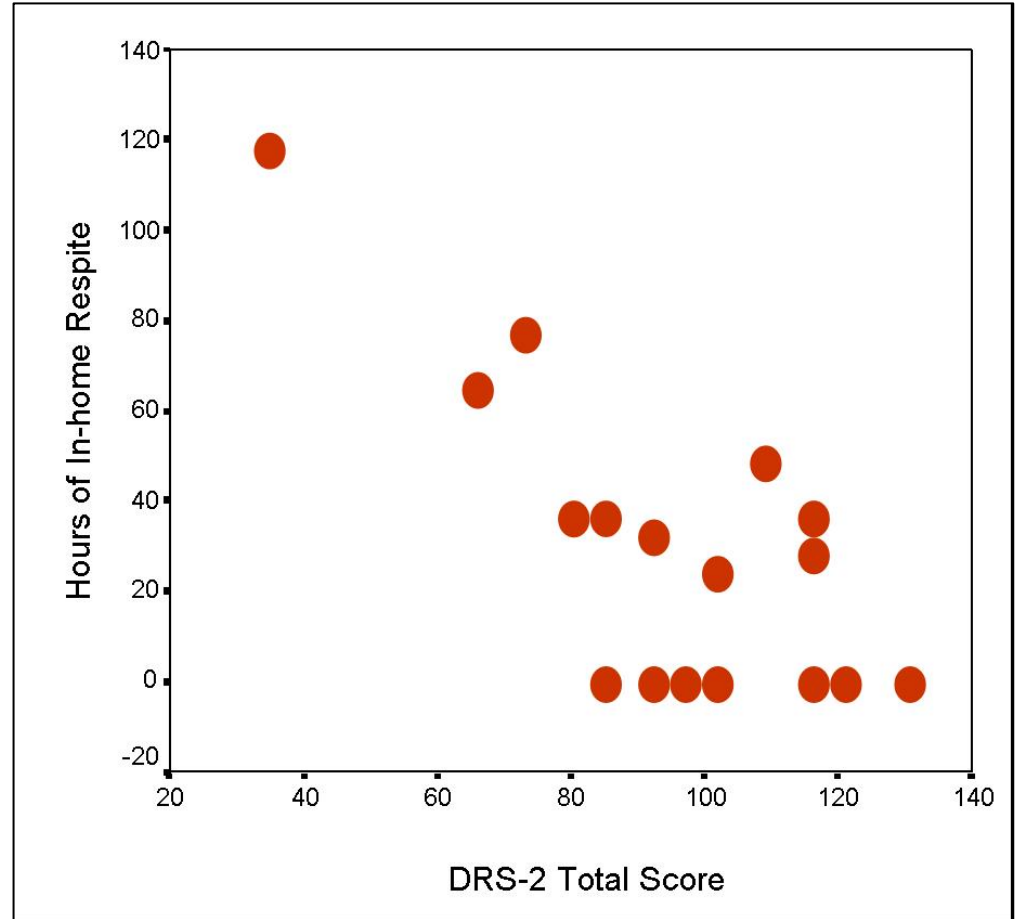
Current service use correlations

	PWD Cognitive	PWD Living skills	PWD Behaviour/mood	Carer strain	Carer Mental Health
Practical	ns	ns	ns	ns	ns
In Home Respite	.001	.032	ns	ns	ns
Out Home Respite	ns	ns	ns	ns	ns

In-Home Respite

X

Dementia Rating Scale



Carers use in-home and out-home respite services differently:

In-home respite usage is well predicted by dementia severity (especially cognitive scores)

BUT...

Utilisation of respite *outside of the home* is NOT related to:

- Dementia severity on any measure.
- Reported carer strain.
- Carer mental health.

Additionally service was not predicted by :

- Amounts of informal care received by carers
- Previous care experience (except Practical care, which was used more readily by those with previous care experience)

Carer satisfaction with services

Good news!

Carers were asked to rate satisfaction with services received in each of the 12 weeks studied (240 ratings).

Almost without exception **carers were satisfied** with the service they received services.

Services very much appreciated

Interviews with carers indicated most had a very positive regard for the services they dealt with.

Services very much appreciated

“ Thehave been very, very good. They make me feel they're really taking care of us and follow-up on things”

“And she ended up listening to me in the most wonderful way...I just felt listened to probably better than anybody ever has about what I was dealing with. She was fantastic. I really valued that phone call...”

Services very much appreciated

“ Theare very caring and I’m very grateful for them.”

“I feel very supported by ...they were very, very supportive and very patient, very patient and the outcome was that we got there in the end very amicably”

Services very much appreciated

“ The...have been really good so I can't knock them because they have helped me in a lot of different things...without them I wouldn't have been able to do anything...”

“The...are a very, very good organisation...they are very nice people, couldn't be nicer...”

Summary

Carers were *under significant strain* which was easily underestimated.

Service usage was consistent with National figures and *not easily predicted* (by carer strain or dementia severity) except In-Home respite which increased with dementia severity.

Carers *valued the services* they received enormously.

Thank You