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L Phillipson

*University of Wollongong*, [lphillip@uow.edu.au](mailto:lphillip@uow.edu.au)

S C. Jones

*University of Wollongong*, [sandraj@uow.edu.au](mailto:sandraj@uow.edu.au)

C Magee

*University of Wollongong*, [cmagee@uow.edu.au](mailto:cmagee@uow.edu.au)

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# Why caregivers of people with dementia don't utilise out-of-home respite services

## Abstract

Carers of people with dementia consistently report an unmet need for respite. Despite this, the overall proportion of carers who utilise available day centre, in-home and residential respite programs tends to be low and, even then, use is often delayed and only at very low intensities. In order to support carers in appropriate and supportive use of respite services, program planners and service providers need a good understanding of the factors influencing use and non-use of respite services. With this in mind, a community based survey of 152 help-seeking caregivers of people with dementia (NSW, Australia) was undertaken to establish what variables make the use of use of day, in-home and residential respite services difficult for caregivers. Results from multivariate logistic regression of survey data reveal that factors such as refusal of the person with dementia to attend services, and low perceived utility of services for the care recipient with dementia, are significantly correlated with caregivers not utilising available services for respite. Such results highlight that whilst the focus of respite services has legitimately emphasised the needs of caregivers for a break, low utilisation of services is likely to persist unless caregivers believe that service use will also be acceptable and of benefit to the person with dementia to whom they provide care.

## Keywords

respite, caregivers, people, dementia, why, don, services, t, utilise, out, home

## Disciplines

Arts and Humanities | Life Sciences | Medicine and Health Sciences | Social and Behavioral Sciences

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# Why Caregivers of people with Dementia don't utilise Out-of-Home Respite Services

L.Phillipson, S.C. Jones & C.Magee

University of Wollongong





## **Centre for Health Initiatives**

University of Wollongong NSW 2522 Australia

Telephone: +61 2 4221 5106

Facsimile: +61 2 4221 3370

[chi-admin@uow.edu.au](mailto:chi-admin@uow.edu.au)

**[WWW.UOW.EDU.AU/HEALTH/CHI/INDEX.HTML](http://WWW.UOW.EDU.AU/HEALTH/CHI/INDEX.HTML)**

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# Dementia



- Progressive disabling neurological syndrome<sup>1</sup>
- No widely accepted treatments or cures<sup>2</sup>
- Many living with dementia require residential care
- Having a co-resident carer improves likelihood that people able to remain living at home longer<sup>3</sup>



# Dementia and Caregiving

- Caring for a family member can have many positive aspects<sup>4-5</sup>
- However, can also be associated with physical and psychological stresses<sup>6-7</sup>
- Particularly if the caregiver feels trapped<sup>8</sup>



# Respite and Caregiving

**Respite** - Temporary relief of the caregiver through provision of substitute care<sup>9</sup>

## Importance to Family Caregivers

- Identified by carers as a critical unmet need<sup>10</sup>
- Enables them to continue role for longer<sup>11</sup>



# Respite Service Use and Non-use



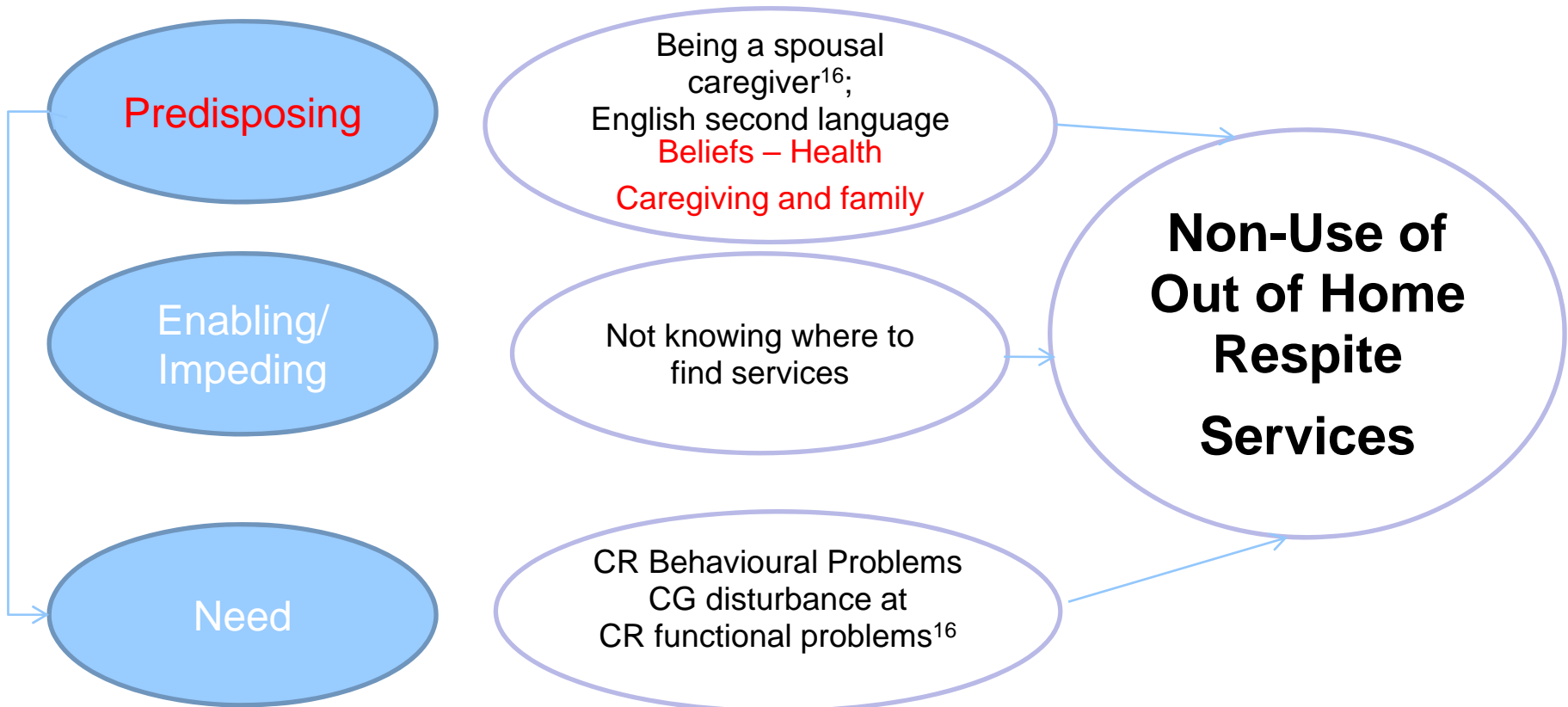
- Proportion of caregivers of people with Dementia using available respite programs is **low**<sup>12,13</sup>
  - 9% of families in US use a day centre<sup>14</sup> and 2% used nursing home respite<sup>15</sup>
  - only 32% with an approval used residential respite in Australia <sup>16</sup>

**Why don't some caregivers use out of home respite services?**





# Andersen Behavioural Model of Service Use<sup>17,18</sup>



# What about service beliefs?



- Health **beliefs** have low correspondence with health service use **behaviours**<sup>19</sup>
- Attitudes towards outcome of specific behaviour better predictor of health service use behaviour<sup>20</sup>
- Knowledge of caregiver beliefs about respite services may:
  - inform strategies to address non-use of particular services
  - improve the success of implementing clinical practice guidelines as part of community care pathways



# Rationale for Study



- **Lack of research exploring the following:**
  - What are the roles of different kinds of caregiver beliefs?
  - How do caregiver beliefs contribute to service non-use?
  - How do beliefs interact with (or inform us about) other factors contributing to service non-use?
- **Aim:** Identify factors that are associated with caregivers *not* utilising out of home services for respite



# Beliefs tested – Health Beliefs

Survey Items	Scoring
<p><b>Stigma Beliefs: 4 items</b></p> <p>Embarrassing to take CR out in public; Self conscious when in public with CR; Avoid company in home; Easy to have guests in home*</p> <p>Dementia is a type of mental illness; I feel embarrassed about CR's memory problems; I feel embarrassed about CR's behaviour problems</p>	<p>4 point scale 1 SD to 4</p> <p>SA;</p> <p>Dementia Stigma (/24)</p>
<p><b>Treatment Beliefs: 5 items</b></p> <p>Early treatment can delay progression; Delaying treatment has negative effect; Medication slows deterioration; Effective treatments are available</p> <p>(Bond et al., 2005). A variety of treatments are available (Authors, unpublished)</p>	<p>4 point scale 1 SD to 4</p> <p>SA;</p> <p>Treatment Score (/20)</p>



# Service Beliefs – TRA and TPB



Survey Items	Scoring	Survey Items
<p>Normative Beliefs</p>	<p>Family - Caregiving for CR is a personal duty; I feel morally bound to provide care</p> <p>Government - The government should: provide more money for respite programs and services to assist carers; help families care for persons at home</p>	<p>4 point scale (SD to SA); 1= A or SA; 2= D, SD or DK Total Family Beliefs (/8)</p>
<p>Behavioural Beliefs</p>	<p>Service Use will lead to negative (or no positive) outcomes.</p> <p>Use may: lead to CR deterioration; cause conflict with CR; or provide no benefit to CR</p>	<p>5 point scale; 1= A or SA; 2= D, SD or DK to any belief</p>

# Service Beliefs – TRA and TPB



	Survey Items	Scoring
Control Beliefs	<p>CR reluctance or refusal: My family member/friend refuses/does not want to attend a day centre (Authors, 2010a, b).</p> <p>Access: I don't know how to access services; or not available when I need them; or not close to where I live; or waiting times are too long</p> <p>Suitability – Can't provide for CR physical or behavioural needs (Authors, 2010a, b).</p>	5 point scale; 1= A or SA; 2= D, SD or DK to any belief



# Research Hypotheses



- **Negative Behavioural, Normative and Control Beliefs** will be associated with day care and RRC non-use
- **Negative Service Beliefs** will be more strongly associated with *non-use* than negative health beliefs



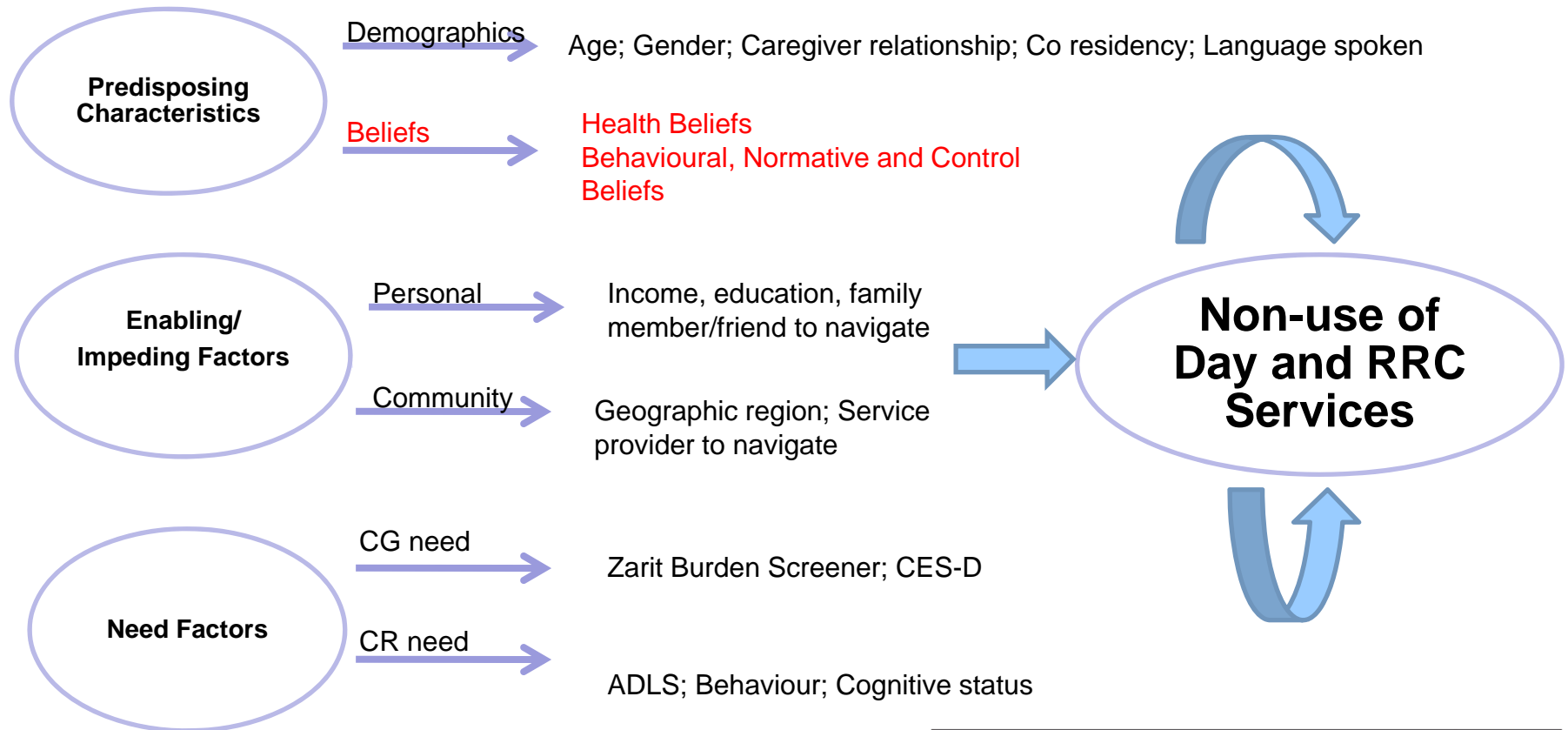
# Survey of Caregivers

- Convenience sample (paper based survey)
- Help-seeking caregivers of people with Dementia
- **152/294** returned completed questionnaires (51.7%)





# Expanded Andersen Behavioural Model of Service Use



# Results – Respite Service Use



- 22 (19.5%) not using any in or out of home services for respite
- 50 (44.2%) not using day care
  - 51 (45.1%) reported an unmet need
- 68 (60.2%) not utilising RRC
  - 66 (58.4%) indicated an unmet need for RRC



# Results



## *Caregivers*

- 57.5% Spousal
- Mean age (66.36 yrs)
- 64.6% female
- 89.4% speak English at home
  
- CES-D
- 28.3% scores indicative of mild depressive symptoms, 28.2% of more major depressive symptoms
- Zarit Burden
- 7% scores indicating they were experiencing a high degree of burden

## *Care recipients*

- Mean age (78.2 yrs)
- 55.8% female
- 90.3% speak English at home
  
- 77% required at least some assistance with their ADLs
- 58% occasionally or frequently exhibited behavioural problems
- 22% had a problem with wandering.
- moderate degree of cognitive impairment (M=19.7; SD 5.39) <sup>46</sup>



# Profile of Day Care Non-Users



Andersen Model	Factors	Day Care Non-use	
Predisposing	CR Refusal/Reluctance	12.11	3.52-41.64*
	CG Expects Negative or no positive outcomes	13.11	3.75-45.89*
	CG Access Beliefs	0.21	0.06-0.78*
Enabling	Assistance to Navigate	0.26	0.06-1.13
Need	CG Depression (CESD)	1.21	1.04-1.39*
	CG Zarit Burden	0.86	0.69-1.08
	CR ADL	1.16	0.25-5.45
	CR Cognition	0.99	0.87-1.13

# Profile of RRC Non-Users



Andersen Model	Factors	RRC Non-use	
Predisposing	CR Refusal/Reluctance	1.512	0.53-4.30
	<b>CG Expects negative or no positive outcomes</b>	6.15	<b>2.02-18.70*</b>
	CG Access Beliefs	1.18	0.44-3.17
Enabling	Assistance to Navigate	0.67	0.22-2.07
Need	<b>CG Depression (CESD)</b>	1.10	<b>1.00-1.21*</b>
	<b>CG Zarit Burden</b>	1.21	<b>1.01-1.44*</b>
	CR ADL	1.68	0.45-6.35
	CR Cognition	1.06	0.97-1.16
	CR Cognition	1.512	0.53-4.30

# Discussion

- First study using theory to compare role of different kinds of caregiver beliefs, regarding *non-use* of out of home respite services
- Negative service beliefs are the strongest correlates with *non-use* of respite services
- Non-use likely to persist unless caregivers believe that service use will be beneficial for the person with dementia to whom they provide care
- Need improvements in service quality and promotion



# Limitations



- Small convenience sample
- Sample may not represent need of caregivers who are yet to actively seek support
- Sample under representative of caregivers from remote geographical regions and of Aboriginal or Torres Strait Islander communities.



# Future Directions

- Promotion of respite services could be improved by highlighting positive outcomes for care recipients as well as for carers
- Need to improve our understanding of preferences of people with Dementia regarding what makes day centres more appealing
- Ways to build trust & confidence and improve RRC image and outcomes



- Identify successful strategies to facilitate transitions from *non-use* to use
- Longitudinal research designs to establish causative relations



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