



# Experiences and management of dementia-related stigma in an Australian population: implications for practice

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## **Dementia related stigma: experiences and management in an Australian population**

*Dementia Collaborative Research Centre – consumers & Carers*

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## Dementia-related stigma

- Research on experiences of dementia-related stigma is limited
- Can be experienced by person with dementia, family member or carer
- Little research examining coping mechanisms
- Useful for education, advocacy, care, quality of life, services, community education



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# Methodology

Descriptive exploratory study

Convenience sample of 14 people diagnosed with dementia  
and their carers (contact facilitated by 2 agencies)

Total of 23 participants – 14 PWD + 9 carers

[10M & 13F; age 64-83, 5x PWD had no carer]

Semi-structured interviews, audio-taped with consent, +  
demographics

Data analysis – verbatim transcription of tapes, four levels  
of thematic analysis to reveal **6 x common dimensions  
to the participants' experience**



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## ***When PWD/carers first noticed something was not right:***

- (Evelyn) 4 years ago: one of the daughters found her wandering, disoriented after a visit to a supermarket
- (Brian) 18 months ago: wandering, as he couldn't find his car during a visit to one of his son's house in Fremantle
- (Helen) 3 years ago: youngest daughter noticed something was wrong
- (John): daughter asked wife if something was the matter with him and suggested seeing a specialist
- (Fred) 4 years ago: forgetful
- (Eileen) 8-9 years ago: losing skills to play golf
- (Peter) 5 years ago: forgetful, noticed strongly by a nurse who took care of him after a stroke
- (Tony): not remembering words, diagnosis of mild cognitive impairment coincided with post-treatment for pneumonia
- (Kaye) 5 years ago: daughter noticed she was not well, depression was initial diagnosis, feeling stupid and unintelligent
- (Malcolm) 4 years ago, forgetful
- (Marian): forgetting people's names, diagnosis coincided with hospitalisation for a fall she suffered
- (Michael) 4 years ago: forgetful
- (Rosemary) 3 years ago: forgetful
- (Shirley): mixed things up while working in the school library



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## Findings

Dimension 1: Social Rejection (concepts = discrimination, feeling different, feelings of hurt & anger)

*'it puts a label on me... people become aware of it ... look at me as being someone marginalized at some stage... not any one person... this attitude towards someone with dementia'*

Dimension 2: Internalised Shame (concepts = internalised embarrassment, perceiving themselves as unwell in comparison to others, wanting to keep illness secret)

*'the label makes things permanent ... can't say it is stress... not going to go away ... reluctance to tell whole story'*



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## Contd.

Dimension 3: Social Isolation (concepts = feeling lonely or isolated, feeling unequal, difficult maintaining normal relationships, presence in society)

*'I's sort of lonely... I walk on my own .... Had to stop playing golf... slowing things down .... Offended'*

Dimension 4: Double stigma -stigma of old age + diagnosis of dementia (concepts = ageism label means symptoms ignored, automatic linking to age, think its normal)

*'GP says she' old, don't worry about her ... not like being senile ...more than just forgetting a few things ... not the same as just forgetting'*



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Contd.

Dimension 5: Courtesy stigma (concepts = experience of carers/family who give it ‘courtesy acceptance’, how they come to terms with diagnosis, denial, limits opportunity to discuss)

*‘my son ... he didn’t want to know that mum has dementia ... denies she has it ..... She’s a bit in denial really ... sisters will talk to me about it but not to H*

Dimension 6: Coping with the diagnosis (PWD & carers)



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# Coping with the diagnosis

## 1. Psychological & practical ways of coping

*'yea, I didn't accept the fact that I had a problem for quite a while .... I sort of denied it for a quite a while ... well it is inevitable .. I just have to accept it .. Can't do anything about it'*

## 2. Support from organisations

*'we have a group of people through AAWA .. We visit every second week ... time together to share ... time with psychologist .. Collect bits of information .. Different experiences'*

## 3. Knowledge & education

*'information about the disease helps us understand ... only new the negatives before we got some information .... Know I am travelling pretty well ... use my illness to educate others (medical students) ... I feel useful'*



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## Limitations

- Small population
- Participants already engaged with support organisation

- Participants well informed
- Limited variability

## Future research

- Larger sample
- Different population
- Involve GP
- Longitudinal study
- Social marketing of messages





What is your experience?

How have you seen stigma experienced?

# Discussion

Stigma experienced presented in different ways:

- *Sense of helplessness then actively challenge diagnosis – both responses experienced by most*
- *Negative impact – loneliness, isolation, depression, altered emotional state*
- *Labelling, images, stereotypes – handicapped, senile, violent, vegetable (self perception, internalised shame)*
- *Devalued and marginalised – third class citizens, nuisance, unequal, ignored (not talked to), incompetent*
- *Isolated – withdrew from friends and activities, family embarrassment, self protection*
- *Strength – share experience, talk to others, join groups*
- *Impact on carers/family – bring family together, cause friction, changes in roles, difficulty maintaining usual life patterns, can be underestimated – can experience stigma ‘by association’*

# Applications: how can we use this information?

*Value of a **diagnosis** (medical diagnosis often brings peace of mind and answers, access to services, explanation for behaviour)*

*Implications of **diagnosis** (reluctance of GPs to diagnose, complexity of referral, labelling)*

*Different **ways of responding** (respond to individual need and avoid stereotyping behaviour)*

*Value of **support networks** (sharing of stories, acceptance and understanding)*

*Importance of **community awareness**, education and understanding (avoid unhelpful reactions, stereotypes, see capacity not loss, avoid associating behaviour with mental illness & age, dispel myths)*



# Applications

*Applications for housing, design, retail outlets, transport, entertainment ....*

***Disability or chronic illness?*** *Community campaigns to better understand illness and empower individuals to live better with condition*

***Staff education*** *to better recognise responses (or lack of)*

***Guidelines*** *for support groups and community programs*

***Needs of younger clients*** *and their families – stigma and children, school, friends etc*

*Education for employers to recognise and support*

***Inclusion*** *not segregation*

