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Experience & management of dementia-related stigma in an Australian population

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DCRC
Dementia Collaborative Research Centres



Translating dementia research into practice





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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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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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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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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Discussion


Stigma experienced presented in different ways: felt

- A sense of helplessness then actively challenge diagnosis – both responses experienced by most
- Negative feelings – loneliness, isolation, depression, altered emotional state
- Perception of labelling, stereotypes – 'felt' handicapped, senile, violent, vegetable (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
- Sense of 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'



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Lessons

Impact of a diagnosis (medical diagnosis often brings peace of mind and answers, not always so with dementia; reluctance to seek diagnosis and reluctance to diagnose)

Different ways of responding (response is individual, avoid stereotyping responses)

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)



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Thank you

Limitations

- Small population
- Participants already engaged with support organisation
- Participants well informed
- Limited by sample

Future research

- Larger sample
- Different population
- Involve GP
- Longitudinal study




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