

Dementia as a source of social disadvantage and exclusion

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Objective: To explore perceptions of the impacts of dementia on people living with the condition and those close to them and examine the relationship between dementia, disadvantage and social exclusion.

Methods: Semi-structured in-depth interviews were conducted with 111 participants: people with dementia (n = 19), carers (n = 28), health-care professionals (n = 21), social workers (n = 23) and service professionals (n = 20). NVivo 11 was used to code descriptions and identify impact areas.

Results: Participants described social, psychological, carer, material, service-based and disparity impacts associated with the experience of dementia. Some of these impacts correspond to social exclusion associated with age, but some are distinctive to dementia.

Discussion: It is argued that dementia generates its own forms of social disadvantage and exclusion. This is in addition to being subject to structural risk factors. The implications of the active effects of dementia as a social phenomenon should give rise to new policy and practice priorities.

KEYWORDS

ageing, dementia, social disadvantage, social exclusion, stigma

1 | INTRODUCTION

One in ten Australians over the age of 65 years and three in ten Australians over the age of 85 years are estimated to be living with dementia. This equates to 425 000 people.^{1,2} Most people (83% of males and 71% of females) with the condition live in the community, with 90% relying on some form of support from family, friends or neighbours.² An increased activism and advocacy by and for people living with dementia,^{3,4} a growing emphasis on creating dementia-friendly communities,^{5,6} and the promotion of dementia as an issue of citizenship, human and political rights,^{7,8} reinforce its significance as a social as well as a medical issue. In this paper, we examine the self-reports of people affected by dementia and look at their experience of their social environment.

1.1 | Dementia, social disadvantage and exclusion

To date, the relationship between social disadvantage and dementia has been based on its connection to other sources of inequality.^{9,10} Hulko argues that the personal identities and social relations of people with dementia exist within interlocking power relations: factors such as sex, ethnicity, class and age determine one's social location and thus the personal experiences of dementia within its socio-cultural context.⁹ According to Winblad et al¹⁰, many of the risk factors associated with dementia cluster in lower socio-economic groups. This is due primarily to the association between deprived areas and a higher prevalence of cardiovascular risk factors in dietary intake, obesity, depression, lack of physical activity, smoking, low levels of social participation and lower levels of education.^{11–13} At the same

time, factors associated with higher socio-economic status, such as occupational status and education attainment, correlate with lower levels of prevalence.^{10,14} Jones suggests that effects are cumulative, with strong correlations between social class and access to dementia diagnosis, treatment and care.¹⁵ The consistent message of public health and epidemiological research is that social disadvantage and dementia are interconnected: with those suffering social disadvantage being more at risk of developing dementia in later life. These studies present the relationship between social disadvantage, exclusion and dementia in a certain way, however: situating social location as the preeminent factor in how dementia is understood and experienced.^{9,15} They do not therefore address the possibility that social identity may be directly impacted by dementia or that unique forms of disadvantage and exclusion arise because of the condition. In contrast, the current study does not begin by examining the social categories that participants fell into, but concentrates on their lived experience arising from living with or close to dementia. From this, it is argued that certain forms of social exclusion arise specifically from the experience of dementia itself.

People with dementia experience the double jeopardy of being old and having a cognitive impairment. While dementia may be linked to processes of social exclusion, leading to an unwanted situation in which people are prevented from engaging in mainstream society, with detrimental consequences for the individual and society,¹⁶ only a handful of authors have pointed to a direct connection.^{17,18} Dementia has not featured prominently in social exclusion research.¹⁶ A more dynamic understanding of social disadvantage is thus required, one that demonstrates more convincingly how individuals experience multiple forms of exclusion arising from chronic illness. Here, we explore this additional possibility: that the experience of dementia itself might produce particular forms of disadvantage and exclusion. This paper elaborates on findings arising from our research on Dementia in the Public Domain¹⁹ where data from a much wider study can be found.

2 | METHODS

In-depth semi-structured interviews of 111 self-selected participants took place in five Australian states. Five different perspectives on dementia were included: the voice of people with dementia ($n = 19$); carers ($n = 28$); health-care professionals ($n = 21$), including nurses, general practitioners, allied health professionals and care service directors; social work professionals ($n = 23$), including care coordinators, community support workers and care managers; and service professionals ($n = 20$), including hairdressers, e-learning and media consultants, small business

Policy Impact

The views of people with dementia, carers and professionals describe impacts of dementia as a social phenomenon. Because dementia generates its own forms of social exclusion and disadvantage, policy and practice interventions need to move beyond assessing demographic risk factors to address forms of psychosocial exclusion that actively affect people's individual, interpersonal and service-related circumstances.

Practice Impact

In terms of research practice, findings indicate that while connected to age-related exclusionary practices, dementia may create additional forms that require specific empirical analysis. This will also require a shift in research activity from starting 'from the outside' through examining external risk factors to 'starting from the inside' of lived experience, plus the relationship between the two.

people, librarians and hospitality staff. In total, 28 men and 83 women were interviewed. Women formed the majority in each participant group excepting people with dementia where men outnumbered women 13 to six. Participants were recruited via professional and consumer organisations and with calling cards placed in community-centres, cafes and shops. All of the people interviewed were living in the community, and none of the people with dementia were in residential care.

All interviews were carried out by the second and third authors, both of whom have had previous experience conducting qualitative interviews, including people with dementia. The interviews, lasting for approximately one hour, were conducted at the interviewers' workplace via telephone for professionals and most of the carers; people with dementia were interviewed face-to-face mostly in their homes, unless they preferred by phone. All interviews were audio-recorded. During the interview, participants were asked to speak about five main topics. An interview protocol, including a set of questions, was developed and pilot-tested with two participants, and discussed with an advisory group from the Consumer Dementia Research Network (CDRN) that included carers and people with dementia. This resulted in minor changes to wording to improve understandability.

The interviews were semi-structured, including a set of questions and subquestions, but allowing for novel directions arising from the interviewees themselves. These formed a common structure to all interviews. Here, we examine one of

those topics arising from the question: *In your mind, what are the most important impacts of dementia?*

Transcripts were read by two research team members, and emerging categories were discussed with the third plus the CDRN. Thematic analysis was then undertaken across responses based on the finalised categories. Using NVivo (QSR International, New York, USA), 24 categories were organised into six impact areas, following independent checking and comparison by the three researchers.¹⁹ The six impacts were as follows: social, psychological, caring, material, service and socio-demographic disparities. Percentage mentions were also calculated that refer to the number of times an impact was coded in relation to all mentions of impact within each group of participants.

All participants gave their informed consent prior to inclusion in the study in accordance with ethical approval by the University of Melbourne Humanities and Applied Sciences Human Ethics Sub-Committee (HESC 1647136). All names presented in the results are pseudonyms. Further details of the sample survey and research methods can be found in our full report.¹⁹

3 | RESULTS

Results have been organised around six emerging impacts of dementia. While the research is essentially qualitative, an indicative percentage of mentions has been added to help the reader navigate the relative importance of the impacts themselves, with the caveat that this is a relatively small sample that does not claim to be statistically representative. Our study, nevertheless, accesses the heterogeneous lived experience of a number of voices close to dementia, including carers and people with dementia themselves.

3.1 | Social impact

Social impact was the most mentioned area for people living with dementia, comprising about a third (34%) of all their references. It was also the most mentioned impact area for social work professionals related (at 30%) and service professionals (at 24%). Health-care professionals and carers referenced the Social impacts as their second priority (at 20% and at 20%, respectively, of all mentions of impact within their voice).

People with dementia and carers communicated a shrinking social world following the onset of dementia and restricted opportunities for social participation. Losing friends was the most common experience relating to social connection, an impact echoed by professional groups:

That's the hardest bit because not only do you lose your thinking process, you lose your friends because they ... don't have dementia and they're still all the same age as me. (William, Person with Dementia, 62 years)

Mention was also made by people with dementia of being made to feel peculiar in public settings and of being treated rudely in shops and businesses.

Carers were more likely to provide concrete examples of exclusion, such as the loss of friends, poor interactions in public and social embarrassment:

... Old neighbours or friends treat you differently because you have got dementia. (Margaret, Carer, 58 years)

... Isolation ... can be the dropping off of friends. They don't get asked to things because, well, they've got dementia. (Amy, Carer, 53 years)

People with dementia tended to communicate the anticipation that they would be treated differently because of their condition, which made some wary of disclosing their condition to friends:

I belong to what's called in our church a family group, and there's about 18 or 20 people in it. I haven't mentioned to any of them that I've been diagnosed with vascular dementia. To be quite honest with you, I don't want to. I'm not quite sure ... how they would react to me ... I don't know what to expect. (Karl, Person with Dementia, 76 years)

Participants from all groups tended to account for the social isolation of people with dementia as a consequence of family, friends and communities not having the skills to interact, engage and include them:

[People with dementia] become very isolated because the network of people in their life often don't have the skills or the knowledge or the understanding to actually respond appropriately in a way that actually values people with dementia. (Fay, Carer, 60 years)

[People] don't understand it so they just don't talk about it, or they are very uneasy talking about it. They don't know a lot about it, they just see it as it's portrayed in the media as a terrible disease that causes death. (Bonnie, Service professional, 48 years)

Only a minority of participants suggested the declining abilities of people living with dementia as the main cause for their social isolation. While people with dementia and their carers desired to remain engaged in family, community and social life,

they feared the loss of social connection that could result from dementia.

3.2 | Psychological impact

All groups mentioned psychological and emotional impact (average 18%), though service professionals mentioned it most (at 24%).

For people living with dementia, responding to cognitive loss generated sadness and frustration. They felt disadvantaged by changes in memory, communication and other cognitive and sensory challenges. Most had come to accept dementia and cognitive loss:

I think I accept that it has been a natural process. It's not something I want but I think it's like a lot of medical situations. It kind of grows on you.
(Bruce, Person with Dementia, 65 years)

Just be who I am and not, sort of, think I've got something peculiar wrong with me ... I'd like people just to accept me as I am. (Audrey, Person with Dementia, 78 years)

For both people with dementia and carers, dementia had ruptured their current lives and future planning. For carers, in particular, planning for the future had become practically and emotionally problematic:

Personally, it is doing the juggle of working and planning for the future when you don't know what the future is. ... In our life we plan for next year's holidays or retirement in ten years, or whatever it is, you're sort of planning for this long-term future, whereas for me now, everything has got a rider on it. (Vron, Carer, 57 years)

... For me, it's been shattered hope, shattered dreams, if you like. (Dorothy, Carer, 60 years)

... It takes away all your hope for the future ... (Ann, Carer, 55 years)

Health-care professionals were the most likely to identify with the uncertainties faced by people with dementia and carers, plus the need to identify future plans while one was still able to:

From the people who I've talked to, usually when they've come into hospital, normally be what they'd be talking about with dementia, and feeling they have no one to talk to about their

understanding of what's coming and planning for the future. (Darren, Health care professional, 36 years)

Carers, along with service professionals, were the most likely to refer to relationship change as a key psychological impact. Carers expressed distress at things like losing the person they loved, not being recognised by their partner, switching roles in the relationship, breakdown in communications and relationship difficulties:

I am now married to a completely different man than I've been married to for 50 odd years.
(Jackie S, Carer, 76 years)

Carers appeared to be under particularly high levels of emotional strain, as evidenced by their reaction to relationship change and the many demands placed on them.

3.3 | Caring impact

The caring impact was most mentioned by carers and health-care professionals (at 17% and 18% of all references to impact within voice, respectively). People with dementia rarely made mention of this impact.

Many participants were of the view that carers were more impacted by dementia than were those living with the condition:

... We often see that ... [carers are] ... the ones that are often looking more ragged than the person with the dementia. (Jill, Health Care, 59 years)

It affects the family more than it affects the actual person. (Rachel, Social Work, 65 years)

Carers often recounted the all-consuming nature of their caring responsibilities, of lives changed completely and the shattering of hopes and dreams. Care was often presented as full-time or 24-hour job, with a number suggesting that they had to be forever monitoring the person they cared for. Significantly, many carers had had to assume responsibility for all household and financial decisions, family and social relations, and crucially, the well-being of their partner. This, alongside the need to remain active and engaged themselves, compounded the level of strain they experienced. Carers also highlighted societal expectations and aspects of the policy environment that pressured them to care.

Carers' views highlighted the ripple effects of dementia, and its negative impacts on individuals, families, friends and communities:

It affects the family, friends, the neighbourhood I guess, everybody that comes into contact with that person. It's a sense of loss and distress and a lot of pressure on the family. That's basically what it boils down to. (Hilary, Carer, 64 years)

It's very confusing, it's not nice for anybody really. It's very draining, very emotional. It's mentally exhausting. (Dina, Carer, 32 years)

Caring responsibilities were recognised as contributing towards social isolation and for its negative effects on health and well-being. Caring for a partner with dementia emerged as a precursor to interlinking forms of social disadvantage, with major repercussions experienced in the areas of work/employment, finances, social engagement and health/well-being.

3.4 | Material impact

People with dementia mentioned material impacts at a rate (20% of all their impact responses) that was double the average for all groups. Most of these references were made to work/employment and transport. When carers mentioned material impacts (at 15%), they were more likely to mention financial difficulties.

Work and employment were a major issue for people with dementia and carers. While some people with dementia recounted being forced from their jobs due to dementia, others made the decision to retire, although often reluctantly:

Because the job I was doing, I was speaking to hundreds of people and all that sort of stuff; and I just can't put two words together anymore. (Simon, Person with Dementia, 62 years)

It took two years to get a diagnosis, and by the time the two years were up, my job had gone. (Kieran, Person with Dementia, 66 years)

Restrictions on travel and getting around, especially in relation to not being able to drive, impacted significantly on people with dementia:

Not driving, so that loss of freedom ... I've got people who've offered to step in and pick me up if needed, but you have to make an appointment about a fortnight beforehand to get a date when they're actually free to look after you. (Jinny, Person with Dementia, 70 years)

Carers were materially impacted in relation to employment and finances/money. The caring role precipitated changes in

type of employment, decreases in working hours and calls for more understanding in the workplace:

I love my work. It was very good but I found [my husband] needed more support so I had to retire ... I wasn't ready to retire ... it was very hard, very hard. (Olivia, Carer, 61 years)

Often carers had to assume full responsibility for household budgets and other financial considerations:

Some of the issues are financial, that's a big one in our family because I'm now the breadwinner ... and so it's changed all of our plans. It has actually limited what we can do financially. (Dorothy, Carer, 60 years)

Some also expressed concerns about the costs of formal services and supports.

3.5 | Service impact

Service impacts generated a high number of references, second only to social impact. Ranging between 21% (health-care professionals) and 27% (carers), the rate of references to service impact was much the same across the five groups.

Access to services was the main concern for all groups within this impact area, followed by negative experiences of professional conduct and diagnosis. People with dementia and carers mentioned diagnosis at a much higher rate than other groups, representing a critical moment in their lives.

Formal diagnosis could be accompanied by exclusionary social expectations:

There's that belief out there, when you get a diagnosis of dementia, your life stops. (Kieran, Person with Dementia, 66 years)

Delays in diagnosis, misdiagnosis, feeling ignored by health-care professionals, and poor attempts at communicating the diagnosis and lack of help available were common experiences.

Following diagnosis, people with dementia and carers had generally struggled in their interactions with a complex service system. In the worst scenarios, they had felt left to navigate the system by themselves:

When he was diagnosed, then they were completely unhelpful. They were like 'here's your diagnosis, see you later'. (Josephine, Carer, 30 years)

Mentions of access to services identified difficulties in obtaining information on available services, locating and accessing

specialists, the costs of service provision, navigating complex service systems, and inappropriate service design and delivery:

... The complexity of what people are required to deal with at a time they're most vulnerable in terms of accessing government aged care services and a whole range of health services is very, very difficult. (Fay, Carer, 60 years)

Both lack of services and inappropriate services being offered were associated with social isolation and social disengagement. This was particularly marked when referring to people who lived alone or without a close relative as a carer. There was significant overlap between access to services and finances/money with many of the view that those with less ability to pay for services were more likely to be disadvantaged. Many felt that the structure of services, including funding rules, eligibility criteria and private health insurance did not work for people with dementia.

People with advanced dementia were thought to be denied certain kinds of services and to be discriminated against:

... The other significant issue is that more and more people that we see affected by dementia are showing severe behaviours, violence and aggression. And ... in my view, there is a systemic, bias bordering on discrimination in the residential aged care market that excludes people like that from getting access to residential aged care. (Paul, Social Work, 41 years)

Negative values and experiences of service provision included factors such as poor staffing and training, meaningless social activities, issues of chemical and physical restraint, rigid timetabling of services and poor physical environments. Such negative characteristics required carers and their partners to remain watchful over the care provided to people with dementia. Many also felt that a negative service environment had contributed to further cognitive decline, early entry into permanent care and carer stress.

Despite these negative experiences, participants also reported positive elements. These related to factors such as committed and passionate caring staff, flexible service delivery, consistency in service personnel, provision of meaningful activities and the delivery of care in dignified ways. Most significantly, such services were felt to reduce the stress that people with dementia experienced, enabled carers to get on with other aspects of their life and helped maintain positive relations between all involved.

Overall, participants expressed the need for increased services, such as community-based programs and community and residential aged care places. This, they felt, needed to be

done equitably and with as much attention to service quality as to quantity. The belief that people with dementia required special kinds of care and support received backing from all groups, particularly the expressed need for meaningful, dignified and age-appropriate supports.

3.6 | Socio-demographic disparity impact

Socio-demographic impacts, such as class, sex, ethnicity or locality, were the least mentioned by all groups (at 8%). However, both health-care and social work professionals mentioned them more often than material impacts (at 9% and 13%, respectively), while service professionals referred to these impacts more often (at 10%) than material impacts and caring impacts. Carers and people living with dementia mentioned this impact at particularly low rates (about 4% each).

There was a tendency among people with dementia and carers to view dementia as individual "bad luck." This runs against the evidence which correlates prevalence and risk with various socio-economic factors. However, most participants felt that dementia itself resulted in declining social status and engagement.

Age of onset was generally considered to be important by each voice group. Specifically, it was believed that younger onset dementia was likely to be more disruptive to individuals and their families and lead to greater levels of social disadvantage:

For people who are diagnosed young, it has significant ramifications for their life ... if a person is diagnosed with what they call younger onset dementia ... they could ... still be working. They could still have a young family. They could still have a mortgage ... so it has economic implications for the family. (Kieran, Person with Dementia, 66 years)

This connection between age of onset and its impact on life stage priorities was the only area where disparity impacts gained common acceptance across participant groups. A more detailed analysis of the effects of age, giving a breakdown of younger and later onset, and analysis based on age and participant voice can be found elsewhere.^{19–21}

4 | DISCUSSION

Findings from this study are based on subjective self-reports of 111 Australians representing different voices close to dementia and do not consist of externally validated observations, yet they indicate important trends that arise

from the lived experience of groups that research has often found hard to reach. The originality of the findings lies in the possibility they hold for reconceptualising the role of social exclusion and stigma associated with dementia as a social phenomenon.

Dementia may, then, present a range of impacts contributing to social disadvantage and exclusion that arise from the social experience of the condition and take forms that affect social integration, material consequences, plus the consequences of caring service systems. While there is some overlap with age-based social exclusion for social, material and service impacts,¹⁶ the consequences of adopting a caring role, plus psychosocial and emotional impacts, may be specific to dementia. This is a different way of looking at the relationship between dementia and disadvantage than is most commonly the case, as it suggests that in addition to seeing forms of pre-existing disadvantage as risk factors, dementia generates forms of exclusion and disadvantage because of the way it is perceived and responded to in the public domain. The evidence presented here gives some support to Cantley and Bowes' conclusion that at least from the perspective of our participants, dementia produces disadvantage regardless of social background.²²

While other studies^{9,15} emphasise the determining influence of socio-economic status, this study is too small to draw conclusions of this type. It can, however, form the basis for more extensive future research. That "disparity" formed the least mentioned impact and the relative absence of reference to forms of pre-existing disadvantage requires further study. Further studies could link these perceptions to behavioural observation as well as using the now identified impacts to examine secondary data sets. A mixed methods study would be the logical next step in order to explore the relationship between condition-generated and structural forms of social disadvantage and exclusion.

As there is not enough space in this article to fully interrogate the possibilities for a new theoretical understanding, a second paper (Biggs, Haapala and Carr, in preparation) will explore the conceptual, policy and research implications of our approach in more detail.

5 | CONCLUSIONS

If dementia generates its own forms of social exclusion and disadvantage, policy and practice interventions need to move beyond assessing demographic risk factors to address forms of psychosocial exclusion that actively affect people's individual, interpersonal and service-related circumstances. This will also require a shift in research activity from starting "from the outside" through examining external risk to "starting from the inside" of lived experience, and examining the relationship between the two.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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REFERENCES

1. Australian Institute of Health and Welfare. *Dementia in Australia*. Canberra: The Institute, 2012. <https://www.aihw.gov.au/reports/dementia/dementia-in-australia/contents/table-of-contents>. Accessed November 7, 2018.
2. Brown L, Hansnata E, La HA. *Economic Cost of Dementia in Australia 2016–2056*. Canberra: The National Centre for Social and Economic Modelling, 2017. <https://www.natsem.canberra.edu.au/publications/?publication=economic-cost-of-dementia-in-australia-2016-2056>. Accessed November 7, 2018.
3. Bartlett R. The emergent modes of dementia activism. *Age Soc*. 2014;34:623-644.
4. Swaffer K. Dementia: Stigma, language, and dementia-friendly. *Dementia*. 2014;13:709-716.
5. Lin SY, Lewis FM. Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *Gerontologist*. 2015;55:237-244.
6. Phillipson L, Hall D, Cridland E, et al. Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia*. 2018;1-16. <https://doi.org/10.1177/1471301218754455>

7. Bartlett R, O'Connor D. From personhood to citizenship: broadening the lens for dementia practice and research. *J Aging Studies*. 2007;21:107-118.
8. Dementia Alliance International. *The Human Rights of People Living With Dementia: From Rhetoric to Reality*. Ankeny, IA: Dementia Alliance International, 2016. <https://www.dementiaallianceinternational.org/human-rights/>. Accessed November 7, 2018.
9. Hulko W. Social science perspectives on dementia research: intersectionality. In: Innes A, Archibald C, Murphy C, eds. *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*. London, UK: Jessica Kingsley; 2004:237-254.
10. Winblad B, Amouyel P, Andrieu S, et al. Defeating Alzheimer's disease and other dementias: a priority for European science and society. *Lancet Neurol*. 2016;15:455-532.
11. Basta NE, Matthews FE, Chatfield MD, Brayne C, MRC/CFAS. Community-level socio-economic status and cognitive and functional impairment in the older population. *Eur J Pub Health* 2008;18:48-54.
12. Ervin K, Pallant J, Terry DF, Bourke L, Pierce D, Glenister K. A Descriptive study of health, lifestyle and sociodemographic characteristics and their relationship to known dementia risk factors in rural Victorian communities. *AIMS Med Sci*. 2015;2:246-260.
13. Wright RS, Waldstein SR, Kuczmariski MF, et al. Diet quality and cognitive function in an urban sample: findings from the Healthy Aging in Neighborhoods of Diversity across the Life Span (HANDLS) study. *Public Health Nut*. 2016;20:92-101.
14. Strand BH, Skirbekk V, Rosness TA, Engedal K, Bjertness E. Income in midlife and dementia related mortality over three decades: a Norwegian prospective study. *eNeurologicalSci* 2015;1:24-29.
15. Jones IR. Social class, dementia and the fourth age. *Sociol Health Illn*. 2017;39:303-317.
16. Walsh K, Scharf T, Keating N. Social exclusion of older persons: a scoping review and conceptual framework. *Eur J Ageing*. 2017;14:81-98.
17. Innes A, Archibald C, Murphy C, eds. *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*. Jessica Kingsley: London, UK; 2004.
18. Österholm JH, Samuelsson C. Orally positioning persons with dementia in assessment meetings. *Age Soc*. 2015;35:367-388.
19. Biggs S, Haapala I, Carr A. *Dementia in the Public Domain: voice and age-based perspectives on social disadvantage and public health campaigning*. Melbourne, Vic.: University of Melbourne. <https://cdpc.sydney.edu.au/research/attitudes-to-dementia/dementia-in-the-public-domain/>. Accessed March 18, 2019.
20. Haapala I, Carr A, Biggs S. Differences in priority by age group and perspective: implications for public health education and campaigning in relation to dementia. *Int Psychogeriatr*. 2018;30:1583-1591.
21. Haapala I, Carr A, Biggs S. What would I want? Dementia perspectives and priorities amongst people with dementia, family carers and service professionals? *Int J Care Caring*. 2019;3:39-57. <https://doi.org/10.1332/239788218x15321005902545>
22. Cantley C, Bowes A. Dementia and social inclusion: The way forward. In: Innes A, Archibald C, Murphy C, eds. *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*. London, UK: Jessica Kingsley; 2004:255-271.

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