**RESEARCH**

**Open Access**

# Dementia is the second most feared condition among Australian health service consumers: results of a cross-sectional survey

Rochelle Watson[1,2*], Robert Sanson-Fisher[1,2], Jamie Bryant[1,2] and Elise Mansfield[1,2]

## Abstract

Fear of disease may act as a barrier to screening or early diagnosis. This cross-sectional survey of 355 people attending outpatient clinics at one Australian hospital found that cancer (34%) and dementia (29%) were the most feared diseases. Participants aged 65 years and over feared dementia the most.

**Keywords**  Dementia, Fear, Community awareness

## Background

Dementia is a leading cause of death and disease burden in Australia [1]. In 2018, dementia accounted for 4% of the total burden, ranking 3rd in the top 20 causes of burden overall, and in the top 2 causes for people aged over 75 years [2]. In 2022 it is estimated there are 487,500 adults living with dementia in Australia [3]. The risk of developing dementia increases with age, with one in 10 Australians aged over 65 years and three in 10 people aged over 85 years diagnosed with dementia [4]. A timely diagnosis of dementia can have important benefits such as: enabling early and proactive intervention to sustain independence for longer; allowing for advance personal planning while the person with dementia may still have capacity; and providing more time to become educated about dementia and establish contact with support services and networks [5].

In line with models of Health Anxiety, it is likely that a subset of individuals who are concerned about a health

condition may delay or avoid seeking medical advice when early signs and symptoms are noticed [6]. This has previously been reported in studies of cancer help seeking behaviour, where participants have reported fear of diagnosis as a key reason for not seeking medical attention [7]. Fear of dementia, or 'Dementia Worry' [8] may act as a barrier to early diagnosis. Although dementia worry is generally associated with a greater likelihood of seeking a diagnosis, more than 10% of people report that they would not agree to be screened if they detected issues with their memory or cognitive function, and 30% report hesitation in agreeing to be screened [9]. A recent review of barriers and facilitators to obtaining a dementia diagnosis found that dementia stigma and fear of a diagnosis were significant contributors to delayed help-seeking in eight studies [10].

In 2010–2011, a series of international studies conducted in the United Kingdom [11], United States [12], France [13], Germany [13], and Spain [13] found that Alzheimer's disease, the most common form of dementia, [14] was the second most feared disease, closely following cancer. A study conducted in the United States that looked at changes in feared diseases between 2006 and 2011 found that the proportion of participants indicating Alzheimer's as their most feared disease had the

*Correspondence:

[1]Health Behaviour Research Collaborative, School of Medicine and Public Health, College of Health, Medicine and Wellbeing, University of Newcastle, W4, HMRI Building, Callaghan, NSW 2308, Australia
[2]Equity in Health and Wellbeing Research Program, Hunter Medical Research Institute, New Lambton Heights, NSW, Australia

greatest increase over time than any of the other illnesses explored [12]. Research in Australia in 2010 found that 63% of people who participated in an online survey feared dementia, which was second only to cancer (66%) [15]. Another Australian study conducted in 2011 echoed these results, with 27% ranking cancer as their biggest fear or their future health, and 11.1% ranking dementia in the top position [16].

International studies have found conflicting results in relation to the impact of age and gender on fear of dementia. A Canadian study of 245 healthy adults found that younger participants self-reported a greater fear of dementia than older participants [17]. Conversely, a German study found that being female and older age were associated with greater fear of dementia among a large sample of the general population [18]. Differences associated with age and gender may be expected given the death and disease burden of dementia in Australia is greater for women than men, and increases with age. [2] However, such differences have not been reported in an Australian setting.

Previous research exploring the most feared diseases did not report on the reasons that people feared these conditions. This limits the potential to identify where community education may be targeted to alleviate fear and reduce potential delays in help-seeking. Substantial literature describes factors which contribute to fear of a cancer diagnosis, which include fears about possible symptoms, physical, social, emotional implications of cancer, and fears about mortality [11]. Several studies have also explored the factors that may contribute to an increased level to dementia worry, including personal experience with dementia, depression and poor subjective health [19–22]. In a 2017 study, participants reported the reasons they would be concerned to share a diagnosis of dementia with family and friends, primarily citing fear that people would treat them, and think about them differently [9]. This study aims to update data about feared diseases in an Australian setting and provide some insight into the general reasons people fear the top listed diseases.

## Methods
### Aims
This study aimed to explore among Australian health service consumers:

1) The most feared health conditions from the top ten causes of fatal burden in Australia [23];
2) Differences regarding the most feared health conditions by age and gender; and.
3) Differences in the main reasons for the top feared conditions.

### Design and setting
A cross-sectional survey of community members attending outpatient clinics at one large, regional Australian hospital was conducted. Outpatient clinics included orthopaedics, cardiology, renal, urology, and general surgery outpatient clinics. The study protocol was reviewed and approved by the Human Research Ethics Committee with oversight of the health district where the participating hospital was located (reference number: 17/03/15/4.06).

### Sample
Eligible participants were adults who were attending an outpatient clinic at the participating hospital; had sufficient English to participate; indicated they were physically well enough to complete an iPad survey; and provided verbal informed consent.

### Recruitment and data collection
Trained research assistants systematically approached potential participants in outpatient clinic waiting rooms and invited participation over a three-month period. Some patients were not invited to participate if they were called in to their appointment prior to being approached. Potential participants who indicated they were well enough to complete the survey, and provided verbal consent to participate, were asked to complete an anonymous online survey on a web-connected iPad. The age category (18–34, 35–44, 45–54, 55–64, 65–74, 75+) and gender of non-consenters was recorded with their permission to enable examination of consent bias.

### Measures
Participants self-reported their age (open text item) and gender (male, female), then were asked "Regardless of any health problems you have had, which of the following conditions do you most fear?". Response options were drawn from the most recent data at the time of survey development regarding the leading causes of fatal burden (years lost due to premature death) in Australia [23]. Response options included: "Coronary heart disease (not high blood pressure or high cholesterol); Dementia and Alzheimer's disease; Cerebrovascular disease (e.g. Stroke); Cancer; Chronic obstructive pulmonary disease (COPD) (e.g. Emphysema); Diabetes; Heart failure; None of these". Participants were instructed to select one option only. To ascertain the reasons for their selection, participants were asked to indicate up to three most important reasons from the following list: "Shortened length of life; Emotional impact (e.g. depression); Social impact (e.g. stigma, feeling isolated); Practical issues (e.g. needing help to do daily tasks); Financial strain (e.g. unable to work or pay for treatments); Physical symptoms and side-effects (e.g. pain, fatigue, vomiting); Legal

issues (e.g. appointing someone to make decisions on my behalf); Other". Where participants selected "Other" they were able to input additional text explaining the reasons. Rather than specific disease-related reasons, the response options were intended to be general in nature, reflecting the various ways the listed diseases may impact on a person's life. The survey was pilot tested with a sample of 20 participants to check acceptability and relevance of the items.

## Statistical analysis

Statistical analyses were conducted using IBM SPSS Statistics v23 [24]. Age and gender of consenters versus non-consenters were compared using chi-square statistics to examine consent bias. Descriptive statistics were calculated to examine the most feared health condition and reasons for fear. Chi-square statistics were calculated to explore differences regarding the most-feared health conditions by categories of age and gender and differences in the reasons selected between participants who chose cancer versus dementia as their most feared condition. Where cells had expected counts less than five, the Monte Carlo method (based on 10,000 sampled tables with starting seed 2,000,000) was used to provide an unbiased estimate of the exact p value as the data set was too large to calculate an exact p value. Sixty-five years was used as the cut-off between the younger and older age groups to correspond with the definition of older Australians used by the Australian Institute of Health and Welfare [25].

**Table 1** Most feared conditions by age, gender and total persons

| Health Condition | Age (Years) | | Gender | | Total Persons (n=355) |
|---|---|---|---|---|---|
| | 18–64 (n=236) | 65+ (n=119) | Male (n=166) | Female (n=189) | |
| Coronary heart disease | 11 (4.7%) | 15 (12.6%) | 14 (8.4%) | 12 (6.3%) | 26 (7.3%) |
| Dementia / Alzheimer's disease | 65 (27.5%) | 39 (32.8%) | 44 (26.5%) | 60 (31.7%) | 104 (29.3%) |
| Cerebrovas-cular disease | 7 (3%) | 6 (5%) | 6 (3.6%) | 7 (3.7%) | 13 (3.7%) |
| Cancer | 90 (38.1%) | 29 (24.4%) | 57 (34.3%) | 62 (32.8%) | 119 (33.5%) |
| Chronic obstructive pulmonary disease | 10 (4.2%) | 2 (1.7%) | 4 (2.4%) | 8 (4.2%) | 12 (3.4%) |
| Diabetes | 13 (5.5%) | 11 (9.2%) | 14 (8.4%) | 10 (5.3%) | 24 (6.8%) |
| Heart failure | 22 (9.3%) | 8 (6.7%) | 16 (9.6%) | 14 (7.4%) | 30 (8.5%) |
| Other | 4 (1.7%) | 1 (0.8%) | 1 (0.6%) | 4 (2.1%) | 5 (1.4%) |
| None of these | 14 (5.9%) | 8 (6.7%) | 10 (6%) | 12 (6.3%) | 22 (6.2%) |

## Results

### Sample

Of 505 eligible participants approached, 355 (70.3%) consented to participate. There was no significant difference in gender between consenters and non-consenters ($\chi^2$=2.67, V=0.07, p=0.102). However, there was a significant difference in age ($\chi^2$=17.24, V=0.22, p=0.007), with a greater proportion of non-consenters in the 65–74 years age category than for consenters. There was an approximately even distribution of male (47%) and female (53%) participants, with a mean age of 55 years (SD=16.9).

### Most feared health conditions

Responses by age, gender, and total persons regarding the most feared health conditions are presented in Table 1. Overall, the most feared condition was cancer (33.5%, 95%CI 28.5–38.3) followed by dementia (29.3%, 95%CI 24.5–34.4), and heart failure (8.5%, 95%CI 5.9–11.5). There was no significant difference in the most feared condition by gender ($\chi^2$=5.55, V=0.13, p=0.697). However, there was a significant difference in the most feared condition between younger and older participants ($\chi^2$=17.24, V=0.22, p=0.022, 99%CI for p 0.018–0.025 by Monte Carlo method). While cancer and dementia remained the top two most feared conditions for both age groups, among younger participants (aged 18–64 years) cancer was the most feared condition (38.1%, 95%CI 32.2-44.3), while among those aged 65 years and over dementia was the most feared (32.8%, 95%CI 24.6–41.9).

### Reasons for the most feared conditions

Reasons for fear were only explored for participants who selected dementia (n=103), cancer (n=111) and heart failure (n=30) as their most feared condition as these accounted for the largest proportion of responses (Table 2). Among the 'other' reasons provided by participants for fearing the top conditions, family history was cited most frequently (dementia n=4, cancer n=9, heart failure n=1).

### Differences in reasons between participants who feared cancer versus dementia

There were statistically significant differences in the reasons for fear of cancer versus fear of dementia. Significantly more participants who selected cancer as their most feared condition than who selected dementia reported shortened length of life ($\chi^2$=63.79, V=0.54, p<0.001), physical symptoms and side effects ($\chi^2$=24.51, V=0.33, p<0.001), and financial strain ($\chi^2$=10.63, V=0.22, p=0.001) in their top three reasons. Significantly more participants who selected dementia, as compared to those who selected cancer, reported social impact ($\chi^2$=39.98, V=0.42, p<0.001), practical issues ($\chi^2$=23.71,

**Table 2** Reasons for fear of conditions

| Reason | Dementia (n = 104) | | Cancer (n = 119) | | Heart Failure (n = 30) | |
|---|---|---|---|---|---|---|
| | n | % | n | % | n | % |
| Emotional impact | 62 | 60.2 | 51 | 42.9 | 6 | 20 |
| Practical issues | 61 | 59.2 | 32 | 26.9 | 10 | 33.3 |
| Social impact | 41 | 39.8 | 6 | 5 | 3 | 10 |
| Physical symptoms and side effects | 25 | 24.3 | 68 | 57.1 | 14 | 46.7 |
| Shortened length of life | 16 | 15.5 | 82 | 68.9 | 16 | 53.3 |
| Legal issues | 14 | 13.6 | 5 | 4.2 | - | - |
| Financial strain | 10 | 9.7 | 32 | 26.9 | 3 | 10 |
| Other | 11 | 10.7 | 16 | 13.4 | 4 | 13.3 |

V = 0.33, p < 0.001), emotional impact ($\chi^2$ = 6.64, V = 0.17, p = 0.01), and legal issues ($\chi^2$ = 6.22, V = 0.17, p = 0.013) as top reasons for fear. There was no significant difference in the proportion of participants reporting family history as a reason between those who most feared cancer versus dementia ($\chi^2$ = 1.40, V = 0.08, p = 0.237).

## Discussion

Cancer and dementia were selected by the majority of participants as the most feared conditions, followed by heart failure. Interestingly, cancer and dementia outranked coronary heart disease, the fourth most feared condition, despite this being the leading cause of fatal burden in Australia [2]. Deteriorating health and wellbeing [7, 26, 27], intensive [7] or limited treatment options [28], and negative impact on loved ones [29–31] are commonly associated with both cancer and dementia. It is possible that the impact of cancer and dementia may be considered more threatening than a heart attack or angina resulting from coronary heart disease.

The finding that dementia is second only to cancer as the most feared condition is consistent with similar international studies [11–13, 32, 33]. Notably, the proportions of participants selecting cancer and dementia as most feared in the current Australian study were much more similar (< 5% difference) than found in studies conducted in other countries. This finding may be influenced by a number of possible factors including: improved treatment and survival rates for cancer [34]; cross-cultural differences in the prevalence and care of people with dementia [35]; and/or increases in dementia prevalence [4]. It is also possible that the characteristics of our sample may have contributed to the closer similarity in cancer and dementia fears compared to previous studies. Previous research suggests that there is a significant relationship between poor subjective health and an increased level of dementia worry [22]. Given our sample were recruited from outpatient clinics and were receiving medical care, it is possible that our sample is comprised of a greater proportion of participants with poor

subjective health, than in previous studies of the general population.

Despite both cancer and dementia being among the top three leading causes of fatal burden for older Australians [2], a significantly greater proportion of participants aged over 65 years feared dementia the most. Fear for loss of autonomy and cognitive decline associated with dementia may be heightened and more salient for these participants given their stage in life, and they may be more likely to know someone or have known someone living with dementia. Further, people in this age group may also be more likely to have known people who have had positive survival outcomes following a diagnosis of cancer and have witnessed the medical advances in cancer diagnosis and treatment in the last century [36, 37].

Dementia was also the second most feared condition across the younger age categories despite not being a leading cause of fatal burden for these groups in Australia [2]. An international comparative study involving five countries found that people were significantly more likely to indicate a fear of Alzheimer's disease if they had a personal family experience with condition [38]. Given the rapidly increasing prevalence of dementia, a large proportion of people of all ages have been touched by the condition. A recent study by the authors found that 46% of a sample of Australian outpatients (N = 446) reported knowing someone with dementia [39], with 22% of participants aged below 60 years having a parent or grandparent with the condition (unpublished data).

The top three most important reasons for fearing cancer or dementia, as indicated by participants, were not surprising given general community awareness of the common symptoms and treatment side-effects associated with these conditions. Particularly noteworthy is the finding that only 15.5% reported shortened length of life as a reason for fearing dementia. This may reflect a lack of awareness among the community about the terminal nature of dementia. Dementia is the second leading underlying cause of death in Australia [1] and a recent systematic review and meta-analysis found the average survival time following diagnosis is 4.8 years [40]. An

international comparative study found that 61% of participants from the US believed Alzheimer's is a fatal disease, compared with less than half of their European counterparts [38]. These findings suggest more community education may be needed regarding the impact of dementia on length of life. It is also possible that participants in the current study perceived the impact of dementia on their quality of life to be more important than life expectancy. Further, reasons for fear of dementia specifically could be more deeply explored in research using qualitative methods. Research examining trends in feared conditions over time in Australia may offer further insight into the impact of disease prevalence and public health programs on community fears about dementia and other conditions.

### Implications for public health

Community awareness of dementia is crucial for early detection, addressing stigma, and optimising care [41]. Community fear of dementia, and other conditions, may have some potential benefit in serving as a motivating factor for individuals to engage in preventative health behaviours [42]. The Extended Parallel Processing Model for effective communication of health messages suggests that public health strategies should increase perceived self-efficacy in responding to the threat of disease (danger control response) so as to ensure fear does not lead to maladaptive behaviours, such as denial or avoidance of early signs and symptoms of dementia (fear control response) [43]. Targeted community education programs focusing on effective strategies to reduce the risk of dementia, early symptoms of dementia and when to seek medical advice, as well as information about how to access the range of support services available to assist people to live well with dementia, may be needed. The current findings highlight the need to address fear of disease and reasons for fear in public health messaging about preventable disease, and appropriately harness its potential as a motivating factor to change behaviour.

### Limitations

The implications of study findings are limited by the measurement of the relative fear of conditions rather than the extent that participants fear each condition. Fear of a condition relative to others does not necessarily imply that the level of fear is sufficient to influence psychological wellbeing, health behaviours, or help-seeking. Future studies should consider exploring the absolute level of fear associated with each condition and how fear affects behaviours related to seeking care and support. Findings replicate those found in previous research with community samples, however generalisability of the current findings to the general population is limited due to the convenience sampling method employed within one hospital setting and limited socio-demographic data on

participants. Binary gender response options were also a limitation and future research should seek to address this to ensure inclusivity. While data was not collected regarding the current health status of participants, participants were recruited from a broad range of clinics to ensure diversity in the sample. Participants were not recruited from geriatric, memory, or oncology outpatient clinics. It is possible that there may have been some underlying bias in responses as a result of existing health conditions of participants, for example one participant who selected cancer as most feared indicated the reason was due to a current diagnosis of cancer. Future research should explore possible associations between existing health conditions and associated fear of disease.

### Conclusions

Dementia is one of the most feared conditions among Australian health service consumers, second only to cancer. Community education programs to increase perceived self-efficacy of individuals in responding to the threat of dementia are needed to ensure fear of the condition does not lead to negative outcomes, such as denial of early signs and symptoms.

#### Authors' contributions
RW was involved in all aspects of the research, including conception and design of the project, acquisition of data, data analysis and interpretation of results, and drafting the manuscript. RS-F contributed to conception and design of the project, interpretation of results, and provided critical review and feedback on the manuscript. JB contributed to interpretation of results, drafting and critical review the manuscript. EM contributed to acquisition of data, interpretation of results, and provided critical review and feedback on the manuscript. All authors read and approved the final manuscript.

#### Availability of data and material
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

### Declarations

#### Competing interests
The authors declare that they have no competing interests.

#### Ethics approval and consent to participate
This study was approved by the Hunter New England Human Research Ethics Committee (reference number 17/03/15/4.06). All methods were carried out

in accordance with relevant guidelines and regulations. Informed consent was obtained from all subjects.

**Consent for publication**
Not applicable.

## References

1. Australian Institute of Health and Welfare. Deaths in Australia. 2022 [Available from: https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/leading-causes-of-death accessed 22 September 2022.
2. Australian Institute of Health and Welfare. Australian Burden of Disease Study: impact and causes of illness and death in Australia 2018. Australian Burden of Disease Study, series no 23 CAT no BOD 29. Canberra:AIHW, 2021.
3. Dementia Australia. Dementia Prevalence Data 2018–2058 Commissioned research undertaken by NATSEM: University of Canberra; 2018 [Available from: https://www.dementia.org.au/information/statistics/prevalence-data accessed 22 September 2022.
4. Brown L, Hansnata E, Anh La H. Economic cost of dementia in Australia 2016–2056 (Report Prepared for Alzheimer's Australia) Canberra: University of Canberra 2017 [Available from: https://www.dementia.org.au/files/NATIONAL/documents/The-economic-cost-of-dementia-in-Australia-2016-to-2056.pdf accessed 22 September 2022.
5. Milne A. Dementia screening and early diagnosis: the case for and against. Health risk & society. 2010;12(1):65–76.
6. Asmundson GJ, Abramowitz JS, Richter AA, et al. Health anxiety: current perspectives and future directions. Curr psychiatry Rep. 2010;12:306–12.
7. Vrinten C, McGregor LM, Heinrich M, et al. What do people fear about cancer? A systematic review and meta-synthesis of cancer fears in the general population. Psycho-oncology. 2017;26(8):1070–79.
8. Kessler EM, Bowen CE, Baer M, et al. Dementia worry: a psychological examination of an unexplored phenomenon. Eur J Ageing. 2012;9(4):275–84. https://doi.org/10.1007/s10433-012-0242-8. [published Online First: 20120922].
9. Tang W, Kannaley K, Friedman DB, et al. Concern about developing Alzheimer's disease or dementia and intention to be screened: an analysis of national survey data. Arch Gerontol Geriatr. 2017;71:43–9. https://doi.org/10.1016/j.archger.2017.02.013. [published Online First: 20170301].
10. Parker M, Barlow S, Hoe J, et al. Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. Int Psychogeriatr. 2020;32(5):611–34.
11. Cancer Research UK. People fear cancer more than other serious illness 2011 [Available from: http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2011-08-15-people-fear-cancer-more-than-other-serious-illness accessed 4 December 2017.
12. MetLife Foundation. What America Thinks: MetLife Foundation Alzheimer's Survey: Harris Interactive. ; 2011 [Available from: https://www.metlife.com/content/dam/microsites/about/corporate-profile/alzheimers-2011.pdf accessed 22 September 2022.
13. Alzheimer Europe. The Value of Knowing: Findings of Alzheimer Europe's five country survey on public perceptions of Alzheimer's disease and views on the value of diagnosis. 2011 [Available from: https://www.alzheimer-europe.org/sites/default/files/alzheimer_europe_survey_2011_the_value_of_knowing.pdf accessed 22 September 2022.
14. World Health Organisation. Dementia Fact Sheet 2022 [Available from: https://www.who.int/news-room/fact-sheets/detail/dementia.
15. Dementia Australia. Australians fear dementia second only to cancer [Media release] 2011 [Available from: https://www.dementia.org.au/sites/default/files/20110310_Nat_MR_PfizerHealthReport2011.pdf accessed 22 September 2022.
16. Medicines Australia. Facing the health of Australians [Research report]. 2013 [Available from: https://www.dementia.org.au/sites/default/files/20130305-rep-FHOA-report-FINAL_(2).pdf accessed 22 September 2022.
17. Laforce R, McLean S. Knowledge and fear of developing Alzheimer's Disease in a sample of healthy adults. Psychol Rep. 2005;96(1):204–06. https://doi.org/10.2466/pr0.96.1.204-206.
18. Hajek A, König H-H. Fear of Dementia in the General Population: findings from the german socio-economic panel (GSOEP). J Alzheimers Dis. 2020;75(4):1135–40.
19. Cutler SJ. Worries about getting Alzheimer's: who's concerned? Am J Alzheimers Dis Other Demen. 2015;30(6):591–8. https://doi.org/10.1177/1533317514568889. [published Online First: 20150204].
20. Cutler SJ, Brăgaru C. Long-term and short-term predictors of worries about getting Alzheimer's disease. Eur J Ageing. 2015;12(4):341–51. https://doi.org/10.1007/s10433-015-0350-3. [published Online First: 20150717].
21. Kinzer A, Suhr JA. Dementia worry and its relationship to dementia exposure, psychological factors, and subjective memory concerns. Appl Neuropsychol Adult. 2016;23(3):196–204. [published Online First: 20151023].
22. Werner P, AboJabel H, Maxfield M. Conceptualization, measurement and correlates of dementia worry: a scoping review. Arch Gerontol Geriatr. 2021;92:104246. https://doi.org/10.1016/j.archger.2020.104246.
23. Australian Institute of Health and Welfare. Australian Burden of Disease Study: impact and causes of illness and death in Australia 2015. Australian Burden of Disease series no 19 Cat no BOD 22. Canberra:AIHW, 2019.
24. IBM Corp. IBM SPSS Statistics for Windows, Version 22.0. Armonk. NY: IMB Corp Released; 2015.
25. Australian Institute of Health and Welfare. Older Australia at a glance. Cat. No: AGE 87. Canberra: AIHW; 2018.
26. Cortes F, Nourhashémi F, Guérin O, et al. Prognosis of Alzheimer's disease today: a two-year prospective study in 686 patients from the REAL-FR Study. Alzheimer's Dement J Alzheimer's Assoc. 2008;4(1):22–9.
27. Tschanz JT, Corcoran CD, Schwartz S, et al. Progression of cognitive, functional, and neuropsychiatric symptom domains in a population cohort with Alzheimer dementia: the Cache County Dementia Progression study. Am J Geriatric Psychiatry. 2011;19(6):532–42.
28. Broadstock M, Ballard C, Corbett A. Latest treatment options for Alzheimer's disease. Parkinson's disease dementia and dementia with Lewy bodies. 2014;15(13):1797–810.
29. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialog Clin Neurosci. 2009;11(2):217–28.
30. Connors MH, Seeher K, Teixeira-Pinto A, et al. Dementia and caregiver burden: a three‐year longitudinal study. Int J Geriatr Psychiatry. 2020;35(2):250–58.
31. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. Psychooncology. 2010;19(10):1013–25.
32. Cantegreil-Kallen I, Pin S. Fear of Alzheimer's disease in the french population: impact of age and proximity to the disease. Int Psychogeriatr. 2012;24(1):108–16. [published Online First: 2011/08/18].
33. Lam TP, Sun KS, Chan HY, et al. Perceptions of chinese towards dementia in Hong Kong—diagnosis, symptoms and impacts. Int J Environ Res Public Health. 2019;16(1):128.
34. Allemani C, Matsuda T, Di Carlo V, et al. Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet (London England). 2018;391(10125):1023–75. https://doi.org/10.1016/s0140-6736(17)33326-3. [published Online First: 2018/02/06].
35. OECD. Care Needed: Improving the Lives of People with Dementia Paris: OECD Publishing. ; 2018 [Available from: https://doi.org/10.1787/9789264085107-en accessed 22 September 2022.
36. Cancer Institute NSW. A history of global cancer breakthroughs 2018 [Available from: https://www.cancer.nsw.gov.au/learn-about-cancer/cancer-breakthroughs accessed 15 April 2019.
37. National Cancer Institute. Milestones in Cancer Research and Discovery. 2020 [Available from: https://www.cancer.gov/research/progress/250-years-milestones accessed 22 September 2022.
38. Blendon RJ, Benson JM, Wikler EM, et al. The impact of experience with a Family Member with Alzheimer's disease on views about the Disease across five countries. Int J Alzheimer's Dis. 2012;2012:903645. https://doi.org/10.1155/2012/903645.
39. Watson R, Bryant J, Sanson-Fisher R, et al. What is a 'timely' diagnosis? Exploring the preferences of australian health service consumers regarding when a diagnosis of dementia should be disclosed. BMC Health Serv Res. 2018;18(1):612. https://doi.org/10.1186/s12913-018-3409-y.

40. Liang C-S, Li D-J, Yang F-C, et al. Mortality rates in Alzheimer's disease and non-alzheimer's dementias: a systematic review and meta-analysis. The Lancet Healthy Longevity. 2021;2(8):e479–e88.

41. Cahill S, Pierce M, Werner P et al. A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. 2015;29(3):255–75.

42. Kim S, Sargent-Cox KA, Anstey KJ. A qualitative study of older and middle-aged adults' perception and attitudes towards dementia and dementia risk reduction. J Adv Nurs. 2015;71(7):1694–703. https://doi.org/10.1111/jan.12641.

43. Maloney EK, Lapinski MK, Witte K. Fear appeals and persuasion: a review and update of the extended parallel process model. Soc Pers Psychol Compass. 2011;5(4):206–19. https://doi.org/10.1111/j.1751-9004.2011.00341.x.