Dementia: opportunities for risk reduction and early detection in general practice

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Abstract. This project aimed to measure general practitioner (GP), practice nurse and patient health literacy about memory problems, dementia and its risk factors. Data were collected from general practices across Australia and a smaller sample in England. Questionnaires explored sources and adequacy of dementia knowledge and a randomised controlled trial tested the intervention of a dementia risk reduction pamphlet on patient knowledge of dementia risk reduction strategies. Data were analysed using SPSS software. The results of 621 questionnaires from patients aged over 30 years showed 37% had memory concerns, 6% recalled having a memory test, 52% would like a memory test and 15% had heard about dementia from their GP. Patients receiving the intervention were significantly more likely to be aware of dementia risk reduction strategies ($P < 0.005$). The results of 153 GP/nurse questionnaires indicated 64% thought a doctor should discuss dementia with patients despite only 21% assessing their dementia knowledge as adequate. There was no significant difference in responses between Australia and England ($P > 0.05$). The frequency of documentation of Mini-Mental State Examination and dementia diagnosis in computerised medical records of patients over 75 years was less than 0.01. These results demonstrate that many adult patients attending GPs have memory concerns, associate dementia with memory loss, and are receptive to information about dementia risk reduction. Most general practitioners and their nurses rate their dementia knowledge as inadequate with few testing for memory problems or discussing dementia with their patients.

Additional keywords: memory problems, health literacy, ‘Mind Your Mind’.

Background

With an ageing population, the lifetime risk of dementia for people who have reached the age of 65 years in 2010 is estimated as one in five (Seshadri and Wolf 2007). In coming years, health professionals from all disciplines will find themselves providing services for people with dementia and their carers (Kamat et al. 2010). General practitioners (GPs) may perceive their dementia knowledge as inadequate and lack confidence in making an early dementia diagnosis or actively managing the illness (Vollmar et al. 2007). Despite this, dementia remains a core part of GP aged care services (Alexander and Fraser 2008). Dementia is commonly perceived as an incurable condition that can occur as you get older and for which little can be done (Trachtenberg and Trojanowski 2008). However, there is increasing evidence that this is not the case and that dementia, although more common in older people, can occur in younger people and is a condition with some potentially modifiable risk factors, creating an opportunity to reduce incidence or delay onset (Stephan et al. 2010). Diagnosis has been shown to be helpful when followed by active management, but training is needed to improve implementation of effective management strategies (Thomas 2010). Many patients may wish to be involved in their own health care with evidence that this can improve their health outcomes (Kaplan et al. 1989), but poor health literacy restricts navigation of health networks, impacting negatively on access and efficacy (DeWalt et al. 2004). Two Australian studies recommend raising community dementia literacy, especially for modifiable dementia risk factors, as a strategy that may reduce dementia incidence (Farrow 2008; Low and Anstey 2009). Health information allows patients to make choices about their health care and written information presented simply can be accessed widely (Wallace and Lennon 2004). Alzheimer’s Australia has produced the one page dementia risk reduction summary, ‘Mind Your Mind’ (MYM), to raise awareness of dementia risk reduction strategies. The GP waiting room could be a distribution point. The National Health and Hospitals Reform Commission report 2009 discusses the importance of consumer engagement in improving health outcomes, with health literacy contributing...
to the engagement process (Bennett 2009). The varied presentations and health journeys of people with dementia are best managed by a multi-skilled team (Jansen et al. 2007). The project rationale proposes that both GP and patient dementia literacy facilitates implementation of strategies to reduce modifiable risk factors and encourages early identification of cases, with the potential to reduce the incidence, delay the onset and improve the quality of life of those living with this challenging condition.

Methodology
The study was designed to explore dementia literacy in a general practice setting and to test whether a waiting room pamphlet would improve patient awareness of dementia risk reduction strategies.

There were three study objectives:
(1) To describe activities, capacity and willingness of general practices to deliver dementia services
(2) To identify patient experiences and understanding of memory problems and dementia, including dementia risk reduction
(3) To test the intervention of a waiting room pamphlet about dementia risk reduction on patient awareness of dementia risk reduction strategies.

The study hypotheses were:
(1) Adult patients linked dementia with memory problems
(2) A waiting room pamphlet could increase patient awareness of ways to decrease their risk of developing dementia
(3) Patients are receptive to discussion about dementia in general practice
(4) Many GPs and practice nurses feel their dementia knowledge is inadequate
(5) Identification and testing for memory problems and dementia in general practice could be improved.

The project team was based in North Queensland, Australia, where most patient data were collected, with a smaller sample from England for comparison. Data about general practice dementia services were obtained from practices in all states and territories of Australia excluding South Australia, and from four sites in England. The study applied mixed methodology including questionnaires, a randomised controlled trial, and data from computerised medical records.

Two one-page questionnaires designed for easy completion were distributed, one to patients aged over 30 years and the other to GPs and practice nurses, both exploring literacy of memory problems and dementia. They included epidemiological questions, questions with a choice of answers and questions requiring free text string answers. Patient questionnaires were distributed through the GP practice network in Australia and personally, mainly in North Queensland but also in four sites in England. All completed GP/nurse questionnaires were the result of personal contact.

All participating practices used computerised medical records to record consultations. Any written records were not accessed, focusing instead on computer data recorded during usual practice activities. Computer data from 14 practices in North Queensland, all using Medical Director software, were used in this study. Data were extracted from patient records using previously trialled software that took 10 min to produce a written report on practice population over 65 years, Mini-Mental State Examination (MMSE) and dementia diagnosis (Millard et al. 2008).

String answers allowed for descriptive responses with multiple themes. Thematic analysis produced a range of topics from the string answers, with more than one topic possible in any string answer (Sandelowski et al. 2007). Analysis using SPSS software (IBM, St Leonards, NSW) enabled each topic to be transformed and recoded into a new dichotomous variable with ‘mentioned’ and ‘not mentioned’ answers, allowing calculation of frequencies, recorded as percentages. Bivariate analysis compared responses by gender, age and country, using date of graduation as a proxy for age in the GP/nurse questionnaire. Patient answers were further analysed for the impact of the pamphlet intervention using Pearson’s Chi-squared test for independence of the answers from patients receiving the pamphlet before and those receiving it after completing the questionnaire. The odds ratio (OR) compared results between groups with significance when $P \leq 0.05$, and the 95% confidence interval (CI) does not include 1.

Results
Sample populations (Table 1)
The patient sample consisted of 621 patients from 22 practices at 14 geographic locations, eight in North Queensland and three in England. The GP/practice nurse sample consisted of 127 GPs and 26 practice nurses from 50 different sites throughout Australia and four in England. The English sample consisted of 21 GPs, one practice nurse and 63 patients. The patient sample was 43% male and 57% female with a median age of

labelled, one-half with ‘pamphlet’ and the other half with ‘no pamphlet’ and were taken from the top of a shuffled pile when offered to patients. Pamphlets were given to the patient before completing the questionnaire labelled ‘pamphlet’ and after completing the questionnaire labelled ‘no pamphlet’. The pamphlet was given to all 621 patients, 299 receiving the pamphlet with their questionnaire and 322 after completing the questionnaire. The questionnaire stated ‘We are surveying people throughout Australia about their understanding of dementia and its risk factors’ and the MYM summary stated ‘Mind your mind to keep your brain healthy’. The patients who received the pamphlet were advised they could use the information to help them complete the questionnaire. Patients completed the questionnaire during their visit to the surgery and the time to read and/or complete the questionnaire varied, with some patients completing the task after their GP consultation.

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50–59 years in Australia and median age 70–79 years in England. The GP sample was 48% female and the nurses 100% female. Date of graduation was used as a proxy for age, with date of graduation ranging from 1965 to 2011. The median graduation decade was 1980–1989 (28%) with 15% graduating 2000–2011 and 6% graduating 1960–1969.

Dementia literacy of patients in general practice (Table 2)
Free text string answers were required for the two questions: ‘What is dementia?’ and ‘Where did you learn about dementia?’
Most answers to the first question included ‘memory loss’ (60.5%), a smaller number included ‘a brain problem’ and a few ‘old age’ with no significant difference between age groups, country or gender (P ≤ 0.050).

The second question produced answers ‘media’(32.5%), acquaintances (30.6%), ‘workplace’ (15.9%) and ‘doctor’ in only a few (1.3%). The only significant difference between groups, P ≤ 0.005, was that male patients were less likely to learn about dementia from their workplace (11/231, 5%, OR = 0.264, CI = 0.150–0.464) than female patients (88/390, 23%).

Patient memory concerns and testing (Table 2)
Many patients (37%) admitted to memory concerns and 52% indicated they would like a memory test with no significant difference between groups (P ≥ 0.05). Of those with memory concerns, 66% wanted a memory test (153/230, OR = 1.798, CI = 1.788–3.516) compared with 44% (171/391) of those who did not have memory concerns. Only 6% (37/621) of all patients recalled ever taking a memory tests, and of these, most (65%) were over 60 years old (24/37). Of those aged over 70 years, only 16% (19/116) recalled having a memory test despite 37% (43/116) having memory concerns and 53% (59/116) indicating they would like a memory test. The majority of patients, 93%, wanted to be told the diagnosis if they had dementia.

Dementia risk reduction (Table 2)
The majority of patients (54%) indicated they thought it was possible to reduce the risk of getting dementia, with a further 37% unsure and only 7% giving a definite ‘no’. This answer showed no significant difference between respondents grouped by gender, age or country. However, 61% (185/303) of those receiving the pamphlet agreed that dementia risk reduction was possible, significantly more (P = 0.001) than those who answered before receiving the pamphlet, 48% (153/318, OR = 0.776, CI = 0.666–0.905). Of those who received the pamphlet, 71% (216/303) described strategies to reduce their dementia risk significantly more (P ≤ 0.005) than the 53% reporting strategies who answered before receiving the pamphlet (167/318, OR = 0.6488, CI = 0.736–0.783). Most patients (78.4%) wanted to learn more about dementia risk reduction, with the female gender, those with memory concerns and those receiving the intervention more likely to want to learn (P = 0.040, P ≤ 0.005, P = 0.038, respectively).

Doctor’s role in discussing dementia and memory problems (Table 2)
Only a small proportion of patients, 15% (96/621) answered ‘yes’ to having heard about dementia from a doctor, with no difference between groups. However, when asked: ‘Whom would you seek help from if you thought you had dementia?’, 81% (503/621) provided the string answer of ‘doctor’ or ‘GP’.

Staff dementia skills (Table 3)
The responses to the GP/practice nurse questionnaire indicated that this workforce was predominantly made up of older health professionals, with only 41% of GPs and 27% of nurses graduating in the last 20 years, with no significant difference between gender or country. GPs were significantly less likely than nurses to lack dementia training (37% vs 62%, respectively), P = 0.029 (OR = 0.714, CI = 0.714–0.986), with no significant difference between country or date of graduation. Despite training, most considered their dementia knowledge inadequate with only 22% of GPs and 15% of nurses responding that their knowledge was adequate. There was no significant relationship between training and adequacy of dementia knowledge.

<table>
<thead>
<tr>
<th>Table 1. Sample population</th>
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<tbody>
<tr>
<td>Sample</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Patients</td>
</tr>
<tr>
<td>GPs</td>
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<td>Nurses</td>
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<th>Table 2. Patient responses</th>
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<tr>
<td>Answers</td>
</tr>
<tr>
<td>Dementia is a memory problem (string)</td>
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<tr>
<td>Dementia is a brain problem (string)</td>
</tr>
<tr>
<td>Dementia is an ageing problem (string)</td>
</tr>
<tr>
<td>Dementia is a mental illness (string)</td>
</tr>
<tr>
<td>Learned about dementia from the media (string)</td>
</tr>
<tr>
<td>Learned about dementia from acquaintances (string)</td>
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<tr>
<td>Learned about dementia from the workplace (string)</td>
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<tr>
<td>Learned about dementia from a doctor (string)</td>
</tr>
<tr>
<td>Do you have memory concerns?</td>
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<tr>
<td>Have you had a memory test?</td>
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<td>Would you like a memory test?</td>
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<tr>
<td>Do you think it is possible to reduce the risk of dementia?</td>
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<tr>
<td>What do you do you think you could do to reduce your risk of getting dementia?</td>
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<tr>
<td>Do you want to learn more about reducing dementia?</td>
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<tr>
<td>If you had dementia, would you want to be told?</td>
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<tr>
<td>Have you heard about dementia from a doctor?</td>
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Data collected in a general practice setting may not reflect the views of the general population. However, most people attend general practices, especially as they get older, and their interaction with the general practice team contributes to illness prevention and timely diagnoses. An understanding of patient health literacy and perceptions of a disease is a useful starting point for dialogue within general practice. By comparing patient disease literacy and expectations of care with health professional confidence in dealing with the disease, we can identify gaps that could be addressed to improve management.

The populations surveyed were drawn from many sites in two countries giving broad representation, with slightly less patients in the working age group in the English sample who were sourced from a commuter town during working hours. The size of the health professional sample reflected the difficulty of engaging this group in answering a questionnaire, albeit short, on a topic that might have held little interest to them. Those health professionals responding were contacted personally and were mainly from regional Queensland, Australia (73%), but answers showed no significant difference between sites.

The computer data is likely to be an underestimate of activities, with many practices still using some manual records and some computer entries not making full use of the software. For example, MMSE result recorded in free text rather than documented in

<table>
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<tr>
<th>Question and responses</th>
<th>GP</th>
<th>Nurse</th>
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<tbody>
<tr>
<td>Date of graduation = post-1990</td>
<td>52/127 41</td>
<td>7/26 27</td>
</tr>
<tr>
<td>Have you received dementia training? = Yes</td>
<td>80/127 63</td>
<td>10/26 38</td>
</tr>
<tr>
<td>Do you consider your dementia knowledge adequate? = Yes</td>
<td>28/127 22</td>
<td>4/26 15</td>
</tr>
<tr>
<td>Who should discuss dementia with patients? = doctor/nurse (string)</td>
<td>79/127 62</td>
<td>19/26 73</td>
</tr>
<tr>
<td>Would you prefer someone else to manage your dementia patients? = Yes</td>
<td>18/127 14</td>
<td>5/26 19</td>
</tr>
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</table>

\( P = 0.199 \). Younger doctors, those who graduated after 1990 (6/52), were significantly less likely to consider their dementia knowledge adequate \( (P = 0.017) \) than those who graduated before 1990 (22/75 \( OR = 0.416, CI = 0.200–0.967 \)). Despite these low figures, 62% of GPs and 73% of nurses responded with the free text string answer that a doctor or nurse was the appropriate person to discuss dementia with patients with no significant difference between country, gender or age group.

**Memory testing in general practice**

A search of Pracsoft medical accounting package (Pracsoft, Crows Nest, NSW) in 14 practices in North Queensland yielded 66 annual health assessments in a population of 672 over 75 year olds consulting in a 6 month period. This equates to 10% of this eligible population having a health assessment. Of these, eight had recorded MMSE in computer medical records and 57 had a documented dementia diagnosis, the majority of whom (92%) were residing in nursing homes.

**Discussion**

Data collected in a general practice setting may not reflect the views of the general population. However, most people attend general practices, especially as they get older, and their interaction with the general practice team contributes to illness prevention and timely diagnoses. An understanding of patient health literacy and perceptions of a disease is a useful starting point for dialogue within general practice. By comparing patient disease literacy and expectations of care with health professional confidence in dealing with the disease, we can identify gaps that could be addressed to improve management.

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The computer data is likely to be an underestimate of activities, with many practices still using some manual records and some computer entries not making full use of the software. For example, MMSE result recorded in free text rather than documented in
practice nurse questionnaire indicate a need to review current dementia training, with most assessing their dementia knowledge as inadequate, regardless of their training. Those who had lacked training were just as likely to consider they had adequate dementia knowledge as those who received training, possibly being unaware of their own dementia knowledge deficits. The risk factors for dementia are similar to those for diabetes and heart disease and doctors and nurses may not be aware that they would help their patients by mentioning this (Kamat et al. 2010). Increasing physical activity by 20% by 2050 may reduce dementia incidence by 5.7% and sustain function for longer in those already with dementia (Teri et al. 2003).

Computer records show a disappointing level of dementia diagnosis documentation and memory testing in the GP patient population over 75 years. A majority of dementia diagnoses were for nursing home patients, possibly a reason for placement in care. This suggests little priority for early diagnosis in today’s general practice.

Conclusions and recommendations

This study has measured dementia health literacy in general practice, gathering the information from questionnaire and using the opportunity to provide information aimed at raising patient knowledge about dementia risk reduction strategies. The results demonstrate a mismatch in patient expectations of GP dementia services and health professional perceived skill in delivering these services. A wider use of appropriate waiting room health information and dementia training that meets the needs of primary care health professionals could facilitate active dialogue about dementia in general practice leading to more effective dementia services and improved opportunities to reduce the impact of dementia on our communities.

Conflicts of interest

None declared.

Ethical approval

This project was approved by the ethical committees of James Cook University, Mackay and Townsville Health Districts. Ethical consent was waived by the Health Ethics Council in England as the questionnaires were voluntary and anonymous.

Acknowledgements

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