

BMJ Open Management of behavioural change in patients presenting with a diagnosis of dementia: a video vignette study with Australian general practitioners

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ABSTRACT

Objective: To test the impact of feedback on the proposed management of standardised patients presenting with behavioural change with a diagnosis of dementia in Australian primary care.

Materials and methods: A video vignette study was performed with Australian general practitioners (GPs) in 2013. Participants viewed six pairs of matched videos depicting people presenting changed behaviour in the context of a dementia diagnosis in two phases. In both phases GPs indicated their diagnosis and management. After phase 1, GPs were offered feedback on management strategies for the patients depicted. Analyses focused on identification of change in management between the two phases of the study. Factors impacting on the intention to coordinate care for such patients were tested in a questionnaire based on the Theory of Planned Behaviour.

Results: Forty-five GPs completed the study. There was significant improvement in the proposed management of three of the six scenarios after the intervention. Older GPs were more likely to refer appropriately (OR=1.11 (1.01 to 1.23), p=0.04). Overall referral to support agencies was more likely after the intervention (OR=2.52 (1.53 to 4.14), p<0.001). Older GPs were less likely to intend to coordinate care for such patients (OR=0.89 (0.81 to 0.98) p=0.02). Participants who felt confident about their ability to coordinate care were more likely to do so (OR=3.79 (1.08 to 13.32) p=0.04).

Conclusions: The intervention described in this study promoted multidisciplinary management of patients with behavioural problems with a diagnosis of dementia. Increasing practitioner confidence in their ability to coordinate care may increase the proportion of GPs who will respond to patients and carers in this context. Older GPs may benefit in particular.

BACKGROUND

This paper addresses a significant and growing problem affecting the well-being of the population. In Australia where the study was

Strengths and limitations of this study

- There is evidence that community support services have the potential to improve the quality of care provided for dementia, but are hampered by a lack of referrals from general practitioners (GPs).
- Following feedback in relation to standardised patients, practitioners were more likely to suggest management options that were consistent with expert opinion.
- A key strength of this study is the presentation of the same cases, in the same way to all GPs.
- Limitations of this study include: (1) GPs had no opportunity to interact with the actor-patient—as such, they had no opportunity to negotiate the health problems that required immediate attention with the patient; and (2) they may have offered appropriate treatment or referral during subsequent consultations.

conducted there are more than 320 000 people living with dementia. This number is expected to increase to 400 000 in less than 10 years¹ and is expected to be almost 900 000 by 2050, at a rate of approximately one person diagnosed every 6 min.² The majority of people with dementia live in the community and for approximately 75% of these individuals, care is provided by family and friends.³ Numerous studies report that challenging behaviours are likely to occur during the progression of the disease and caring for a person with dementia is more stressful than caring for a person with a physical disability.^{4–6}

Pearlin *et al*⁷ offered a model of caregiver stress that identifies four main areas that contribute to caregiver stress: the background context (such as level of support and impact of other life events); the primary stressors of the illness (such as the level of help required by the patient and behavioural and psychological problems in dementia); secondary



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role strains (such as family conflict and social life); and intrapsychic strains such as personality, competence and role captivity of the caregiver. Such stress impacts on the quality of life of the carer directly and ultimately also on the well-being of the person with dementia.⁸ Offering support with understanding and managing behavioural change that may be embarrassing, distressing, annoying or dangerous may alleviate stress in all four areas. It is also possible that the behaviour of the carer may also be a cause for concern.⁹

In many countries carers are able to seek support from a general medical practitioner. Regardless of the underlying cause of the problem there is significant scope to support the carer by providing information on an ongoing basis, with specific information about services and advice regarding the carer role.¹⁰ However, carers report that too little information is provided about how to deal with behaviours that challenge and how to access support services.¹¹ The healthcare experience of people with dementia and their caregivers is a complex and dynamic process, which could be improved for many people. Understanding these experiences provides insight to potential gaps in existing health services.¹² Indeed experts have called for the research emphasis to shift towards the development and evaluation of interventions, particularly those providing support after diagnosis.¹³

Often the first healthcare professional consulted is the general practitioner (GP). For four key reasons it is challenging to research the interaction between GP and families when they present for advice about behavioural changes in the context of a dementia diagnosis. The timing and demand for such consultations is unpredictable. Participants may find it distracting to have video cameras or audio equipment recording the consult. Getting informed consent from distressed, embarrassed or angry people or where a person with dementia is involved would be challenging and possibly unethical. Finally the outcomes of such consultations would have many confounding variables as doctors, patients, carers and circumstances vary.¹⁴ Video vignettes, in which actors present the behaviours of interest, are one way to address these challenges and the aim of this study is to deploy such vignettes to explore the management of people presenting to GPs in the context of a dementia diagnosis.

METHODS

Participants were recruited from a network of 150 GPs across Australia who had previously participated in similar video vignette projects. GPs were emailed invitations and these were supplemented with follow-up personal invitations to the invitees who did not initially respond. Participants were remunerated with \$A50 for their contribution.

MATERIALS

Twelve video vignettes were developed; six examples of changed behaviour associated with behavioural and

psychological symptoms of dementia were each portrayed in a pair of vignettes. Each vignette depicted a patient and their carer with clear indications for specific management, including referral, prescription, reassurance and/or investigation. The vignettes were developed by an expert panel consisting of three GPs, in consultation with a team of behaviour consultants from the Dementia Behaviour Management Advisory Services which is one of the programmes provided through Alzheimer's Australia, Western Australia. The scenarios reflected clinical challenges regularly presented by patients with cognitive impairment to GPs in Australia.⁶ The expert panel also suggested the management for each case with details of prescription, referral for specialist management, and laboratory investigation (figure 1). The management was proposed and refined through consultation until a consensus was reached from the expert panel. The vignettes were then prepared as short video monologues by the actor-patients. See example in online supplementary video file. The video included an off-camera commentary by an actor-doctor describing relevant signs to be found on clinical examination. Participation in the study was via the internet. Each vignette was accompanied by a patient medical record including the patient's recent history, examination and investigation results. Participants were asked five questions after watching each video vignette:

1. What is your diagnosis?
2. Would you prescribe something? If so, what?
3. Would you refer the patient? If so, to whom?
4. Would you order tests? If so, which tests?
5. What would you advise the patient/carer?

Participants were provided written feedback in the form of a letter from a specialist clinic, a solicitor's letter or a newspaper report a week after watching the first set of videos. Each of these suggested that the patient in question had experienced harm in the ensuing weeks. For example, the patient who had difficulty driving had been involved in a road traffic accident, the patient with night time wandering had drowned, the patient with side effects of drug treatment was hospitalised, and so on. The letter also offered reference to resources of support to such patients.

The project was completed in three stages:

Phase 1: Participants were invited to view the first set of six videos (Scenarios A) and immediately describe their management of the patient depicted. They then completed a Theory of Planned Behaviour (TPB) questionnaire as described below.

Feedback: Within the subsequent 2 weeks, all participants received feedback on the management of the cases viewed.

Phase 2: All participating GPs were invited to view the second set of six videos (Scenarios B) and again immediately describe their management of the patient depicted.

TPB questionnaire^{15 16}: the development of the questionnaire is described in online supplementary appendix 1.

Adverse drug reaction	Prescribe: Reduce does of Aricept. Refer: for community support e.g. Dementia Behaviour Management Advisory Services Advise: On guidelines for the prescription of Aricept.
Increased need for carer support	Prescribe: Nil indicated Refer for community support- In Australia refer to Aged Care Assessment Team (ACAT). Offer leaflets from Alzheimer's Australia
Dangerous driving	Prescribe: Reduce does of Risperidone if possible Refer: Occupational therapy driving assessment Offer leaflets on driving and dementia Advise patient to stop driving pending assessment.
Sexual abuse	Prescribe: Nil indicated Refer: To Community Aged Care Team to monitor behavior Advise: sexual assault must stop.
Precarious social circumstances	Prescribe: Risperidone. Refer: ACAT for residential care/respice referral to ACAT for Extended Aged Care at Home Dementia package – support during the day provision of meals Education and support/counselling through AAWA for children/carers. Referral to Dementia Behaviour Management Advisory Service for managing confusion at night.
Financial problems	Prescribe: Consider antidepressant if patient clinically depressed. Referral to Alzheimer's Australia 'Younger On set Dementia' key worker for case management Referral to DBMAS for sleep assessment Counselling on dementia to facilitate better understanding Financial implications – carer allowance Future planning – wills power of attorney

Figure 1 Specific recommendations for management of cases (AAWA, Alzheimer's Australia WA; DBMAS, Dementia Behaviour Management Advisory Service).

Statistical analysis

Standard descriptive statistics were used to summarise the profile of the participating GPs using Stata V.12.1 statistical software (Texas, USA). The main outcome measure was the proportion of patients (scenarios) appropriately managed in each set of vignettes. Appropriate management was defined as agreement with an expert panel on the diagnosis, referral recommendation, drug management and advice given to the patient or carer. Agreement was assessed separately on the basis of each of these criteria. The main hypothesis was that there would be a difference in management between the two phases of the study, as a result of the feedback received following phase 1.

Thirty GPs would lead to 360 observations (6 vignettes for each GP, preintervention and postintervention). With internal correlations in the data set due to the repeated observations made by each GP, it is difficult to be precise about the minimum sample size required to demonstrate a change in management. However, this number is considerably larger than that required to demonstrate a difference of moderate size among independent observations with 80% power and $\alpha=0.05$.¹⁷ Hence this number of GPs was expected to be adequate for the study. The primary hypothesis was assessed using

McNemar's test (univariate test). A logistic regression model was used to assess whether any of the GP demographic variables were associated with appropriate management. The model took into account the correlations between assessments made by the same GP (as a cluster effect using Stata). Initially, a model was fitted to the data including the following variables: (1) demographics of GPs and primary practice, including age, gender, country of origin, years of GP experience, experience level (registrar or consultant), whether they were Fellows of the Royal Australian College of GPs (FRACGP), clinic remoteness, status in the practice (eg, principal/registrar), number of patients seen per week, hours of consultation per week, whether they consulted in English only, number of years since graduation, number of GPs working in the clinic, number of sessions worked per week); (2) study case; and (3) study phase. A backwards elimination strategy was used to identify the most parsimonious model (by dropping the least significant variable, one at a time, until all variables remaining in the model were statistically significantly associated with the outcome). The only exception was that the study case and study phase were retained in the final model regardless of their significance, so that other results could be interpreted after adjustment for these variables.



The results were presented as ORs for appropriate management decisions, along with their 95% CIs and p values. Following convention, a p value <0.05 was taken to indicate a statistically significant association in all tests.

Questions constituting the attitude norm items were assessed for internal consistency using Cronbach's α statistic. A similar logistic regression model was then used to explore variables associated with the GPs intention to coordinate care, using attitude, subjective norm and perceived behavioural control as the independent variables along with the demographic variables.

RESULTS

Forty-five GPs consented to participate and all completed the study. Those who participated in the study were younger than the average GP in Australia, there were more female GPs, more registrars and more Australian graduates. There were more participants from Western Australia and more participants doing fewer hours and seeing fewer patients than the national average (table 1). Overall most participants correctly diagnosed cases in the study's two phases although the proportions correct were quite modest in some cases (table 2). However, in phase 2, fewer recognised the case of sexual abuse and precarious home circumstances than in phase 1. There were some statistically significant differences in the management of cases in phase 1 compared with phase 2 (table 3). Specifically, participants were more likely to refer to support agencies when indicated.

Regression analysis modelling factors associated with management that is consistent with expert opinion are shown in table 4. Referral that was consistent with expert opinion was more likely if the participants graduated in Australia, and was also more likely in phase 2 of the study.

Theory of planned behaviour

Internal consistencies (Cronbach's α s) were calculated for the questions constituting the intention ($\alpha=0.72$), subjective norms ($\alpha=0.71$), perceived behaviour control ($\alpha=0.63$) and attitude norms ($\alpha=0.72$) dimensions. These values all show good internal consistency.

Only two participants said that they would 'maybe' consider coordinating the care of patients with cognitive impairment. These respondents were grouped with those who responded that they would not consider this role (n=16) in the following analysis.

Table 5 shows the ORs and their 95% CIs for coordinating the care of patients with cognitive impairment. Attitudes and behavioural control were positively associated with GPs' intention to consider coordinating the care of patients with cognitive impairment (p<0.05 in table 5). GPs' perceived level of difficulty of devising a management plan for these patients or subjective norm were not associated with GPs' management intention.

Older GPs were less likely to consider coordinating the care of such patients.

DISCUSSION

These data indicate that the management of patients with behavioural problems associated with cognitive

Table 1 Participant demographic information (n=45)

	Participants n=45	National n=43 400
	Mean (SD)	
Age, years	41 (10.8)	50.5 years ²⁷
Years after graduation	16.8 (11.3)	No data
Years as GP	11.6 (10.9)	No data
Number of GPs in the clinic	6.8 (4.2)	7 or more GPs (29%) ²⁸
GP sessions/week	7 (3)	No data
	N (%)	
Gender, male	22 (51.1)	56% ²⁸
GP registrar (GP in training), yes	9 (20)	1000 (3.8%) ²⁹
FRACGP, yes	28 (62.2)	54% ²⁸
Accredited, yes	45 (100)	91% ²⁸
Position		
Principal	8 (17.8)	No data
Non-principal	28 (62.2)	No data
Others	9 (20)	No data
State		
NSW	10 (22.2)	31.6% ³⁰
Queensland	2 (4.4)	17.7%
Victoria	9 (20)	26.2%
South Australia	3 (6.7)	9.2%
Tasmania	0 (0)	2.4%
Western Australia	20 (44.4)	10%
Australian Capital	0 (0)	1.8%
Territory		
Region of the clinic		
Capital	21 (46)	
Other metropolitan	18 (39)	
Large rural	2 (4)	
Small rural	3 (7)	
Remote centre	2 (4)	
Major cities	30 (66.7)	71%
Other	15 (33.3)	
Country of graduated university		
Non-Australia	11 (24.4)	
Australia	34 (75.6)	67%
Patient seen/week		
<100	24 (53.3)	No data
100–149	12 (26.7)	No data
150–199	9 (20)	No data
Direct patient care hours/week		
<21	14 (31.1)	11%
21–40	20 (44.4)	56% ²⁷
41–60	11 (24.4)	33% ²⁷
Non-English consultation		
No	39 (86.7)	
Yes, <25%	6 (13.3)	

FRACGP, Fellows of the Royal Australian College of GPs; GP, general practitioner; NSW, New South Wales.

Table 2 Appropriate diagnosis of cases per phase of study

Diagnosis	Phase 1 (n=43) Correct		Phase 2 (n=43) Correct		p Value
	N	%	N	%	
Case 1 Adverse drug reaction	31	69.8	21	48.8	0.06
Case 2 Sexual abuse	41	95.4	26	60.5	<0.001
Case 3 Precarious social circumstances	30	69.8	18	41.9	0.008
Case 4 Dangerous driving	18	41.9	20	46.5	0.02
Case 5 Increased need for carer support	16	37.2	26	60.5	0.02
Case 6 Financial problems	39	90.7	43	100.0	0.13
Total (n=270)	174	67.4	154	59.7	0.04

impairment who present to GPs can be improved with feedback. The feedback had some medical information but in some cases was simply a note of what might have happened to the patient without any intervention or support that could have been arranged by a GP. Some GPs, notably those who were older, were reluctant to coordinate care for patients in these circumstances. Some felt that care coordination would be ineffective and unrewarding, and they lacked confidence in their abilities in these circumstances. Similar data have been

reported in relation to GPs in the UK and Germany.^{18 19} These themes have also been reflected in research from the USA where, in one study, practitioners reported about insufficient time, difficulty in accessing and communicating with specialists, low reimbursement, poor connections with community social service agencies and lack of interdisciplinary teams.²⁰

Interventions to link carers with community support agencies have been shown to have promising results.²¹ This study found that alerting GPs to potential adverse

Table 3 Appropriate management of cases by phase of study

Management	Phase 1 (n=43) Correct		Phase 2 (n=43) Correct		p Value
	N	%	N	%	
Case 1 (adverse drug reaction)					
Reduce dose of donepezil (n=45)	12	26.7	–	–	
Refer to community support agency	9	20.9	20	46.5	0.02
Educate carer on side effect of donepezil	12	27.9	21	48.8	0.05
Case 2 (sexual abuse)					
Advice: sexual abuse at phase 1 and daughter to discuss father's dementia with neighbours/current behaviour problems at phase 2	31	72.1	24	55.8	0.17
Refer: to community support agency	29	67.4	36	83.7	0.14
Case 3 (precarious social circumstances)					
Refer to community support agency	34	79.1	41	95.4	0.04
Prescribe pain killers/consider risperidone for wandering	–	–	4	9.3	
Advice: leaflets on wandering, review 2 weeks/1 month	33	76.7	29	67.4	0.34
Case 4 (dangerous driving)					
Refer to occupational therapy driving assessment/community support agency	32	74.4	35	81.4	0.55
Advice: leaflet on driving and dementia/stop driving	38	88.4	39	90.7	1.00
Case 5 (increased need for carer support)					
Refer to community support agency	32	74.4	42	97.7	0.002
Advice: see daughter at another appointment	32	74.4	34	79.1	0.75
Case 6 (financial problems)					
Refer: to community support agency /psychiatrist/counselling at phase 1 and to neurologist/community support agency at phase 2	29	67.4	29	67.4	1.00
Advice: suggest alternative employment	18	41.9	25	58.1	0.14

**Table 4** Factors associated with management that is consistent with expert opinion

	Management consistent with expert opinion		
	Referral OR (95% CI), p value	Prescription OR (95% CI), p value	Tests OR (95% CI), p value
Age	1.11 (1.01 to 1.23), 0.04	–	–
Years after graduation	0.91 (0.82 to 1.00), 0.046	–	–
Gender	–	–	–
Female		1.00	
Male		0.62 (0.48 to 0.82), 0.001	
Graduate in Australia			–
No	1.00		
Yes	2.77 (1.54 to 4.97), 0.001		
GP registrar	–	–	
No			1.00
Yes			0.57 (0.34 to 0.98), 0.04
Non-English consultations	–		–
No		1.00	
Yes, <25%		0.57 (0.40 to 0.83), 0.003	
Cases			
1. Adverse drug reaction	1.00	1.00	1.00
2. Sexual abuse	8.03 (3.93 to 16.43), <0.001	9.89 (4.41 to 22.22), <0.001	1.00 (0.62 to 1.62), 1.00
3. Precarious social circumstances	18.69 (8.83 to 39.55), <0.001	0.95 (0.64 to 1.43), 0.82	1.73 (1.03 to 2.90), 0.04
4. Dangerous driving	9.25 (4.42 to 19.35), <0.001	0.69 (0.43 to 1.11), 0.13	2.81 (1.51 to 5.26), 0.001
5. Increased need for carer support	16.81 (8.66 to 32.64), <0.001	0.83 (0.53 to 1.30), 0.42	2.41 (1.44 to 4.03), 0.001
6. Financial problems	4.90 (2.37 to 10.13), <0.001	2.39 (1.38 to 4.11), 0.002	1.11 (0.64 to 1.91), 0.72
Phase			
1	1.00	1.00	1.00
I2	2.52 (1.53 to 4.14), <0.001	0.97 (0.79 to 1.20), 0.79	0.86 (0.60 to 1.23), 0.41
Pseudo R square	0.20	0.11	0.04

GP, general practitioner.

outcomes, including the medicolegal implications of a failure to act increased the odds of people being referred to supportive agencies in subsequent clinical scenarios. These results are promising in the light of previous evidence that local Alzheimer's Association chapters have the potential to improve the quality of care provided for dementia, but are hampered by a lack of referrals from GPs.²²

In this study the feedback intervention had the greatest effect on referral to supportive agencies. Changes in diagnostic accuracy were mixed. We note that diagnosis is a comparatively 'hard' construct that medical training equips doctors to handle. However referral to a myriad of (changing) agencies is less 'medical' and therefore more amenable to improvement through education and awareness. Such observations have been reported previously in the literature.^{23 24}

Improvements in referral to supportive agencies, if they were reflected in actual clinical practice, would have the potential to reduce adverse incidents and promote better outcomes and satisfaction for patients. For example, in phase 1 of this study, in the case of patients with an adverse drug reaction to medication, only 20% of participants referred to a community support agency to support the carer, while in phase 2 this proportion increased to 46.5%. Similar trends towards referral were observed in the other cases (except for those involving financial problems). Referral increases the potential for team work in primary care and makes it more likely that patients can be maintained in the community for longer. The value of medication review, behavioural modifications, and referral to outside services has been underlined in respect to the role of GPs in coordinating the care of people living with dementia.²⁵

Table 5 The OR of difficulty of developing a management plan and TPB scores associated with GPs' intention to consider coordinating the care of patients with cognitive impairment

	GPs' intention to coordinating the care of patient with cognitive impairment	
	OR (95% CI)	p Value
TPB		
Difficulty	0.93 (0.44 to 1.98)	0.85
Attitudes norm	3.30 (1.00 to 10.85)	0.05
Subjective norm	1.04 (0.46 to 2.35)	0.93
Behavioural control	3.79 (1.08 to 13.32)	0.04
Demographic		
Age	0.89 (0.81 to 0.98)	0.02

GP, general practitioner; TPB, Theory of Planned Behaviour.

A recent literature review reported that two other factors are also likely to be important in the context of cognitive impairment namely, attitudes and beliefs.¹⁹ These issues were evaluated by the TPB questionnaire in this study. The responses indicated that a positive attitude to the management of behavioural problems in cognitive impairment and greater confidence in managing such cases made it more likely that participants would choose to coordinate the care of patients in these circumstances. The feedback offered may have increased confidence by identifying the sources of support that may have been overlooked in the management plans as drafted in phase 1 of the study.

Strengths and limitations

In a study involving bona fide patients, GPs would be unlikely to consult six patients with carers of people with dementia within the study period. However, a key strength of this research was that all GPs were exposed to the same cases presented in the same way. The use of standardised patients also demonstrated the possibility of harm to patients if the study was observing 'real' patients which would have rendered it difficult to complete without intervening. For example, it would have been unethical in research to record poor practice in relation to the patient exhibiting night time wandering because of the significant risk of harm. Second, as the cases were all standardised actor-patients, the GPs were not required to recruit patients and obtain informed consent, therefore data were obtained for all cases. Such advantages have facilitated research with similar challenging scenarios in the past.²⁶ Three limitations also warrant mention. First, there was no doctor-patient interaction. In practice, this may influence management decisions. Second some patients who were not referred to a support agency may have been referred later following investigation by a GP—for example, routine blood tests or infection screens to rule out an organic cause for the altered behaviour. However an exploration of this possibility was beyond the scope of this study. Finally, ideally each of the scenarios would have been randomised so that half the group got Scenario A and half got Scenario B before the intervention. Using the survey platform deployed in this study this idea was deemed impractical and so it is possible that nuances in the scenarios may have had an impact on the observed effect. However we note that not all scenarios in phase 2 were more likely to be correctly diagnosed and so the effect of this confounder is likely to be minimal.

Clinical implications

Feedback to participating GPs promoted management plans that were consistent with expert opinion. However, in some cases, there were still significant numbers of participants who failed to make the correct diagnosis or to suggest treatment plans that reflected expert opinion. In this study it was not clear whether this was because participants disagreed with the expert panel or failed to

assimilate the feedback into their later responses in the study. While there was an improvement in referring cases to community support agencies in phase 2 of this study, it would be unsafe to assume this was entirely related to the feedback received after phase 1. Further evidence that such a brief internet-based educational programme may enhance care when supporting actual patients and their carers may be required before it can be unequivocally recommended.

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Contributors MJ, PM, PN and GP conceived the project and oversaw the design of the study. XM and RP conducted statistical analyses and analysed the data. VP coordinated the study. MJ and VP oversaw the collection of data and implemented the study. All authors interpreted the data and results, prepared the report and the manuscript, and approved the final version.

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