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Final Report

A feasibility study of a nursing intervention to assist General Practitioners with best practice identification and management of dementia

Dementia Collaborative Research Centre

Assessment and Better Care

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Translating dementia research into practice

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Introduction

This report presents the findings from two separately funded but intricately linked DCRC projects conducted by The University of Newcastle, Discipline of General Practice. The initial pilot study, " *A pilot study of a nursing intervention to assist General Practitioners with best practice identification and management of dementia*", led to an extension project, "*A feasibility study of a nursing intervention to assist General Practitioners with best practice identification and management of dementia*".

Background

What is dementia?

Dementia is the term covering a range of conditions characterized by impairments to memory, problem solving and thinking affecting language, social skills, emotional reactions, personality and intellect. There are different types of dementia with the two commonest being Alzheimer's disease and vascular dementia.

Prevalence

There were estimated to be 266,574 people with dementia in Australia in 2011, with an expected increase to 553,285 people by 2030, and to 942,624 people by 2050. Dementia prevalence is expected to grow by around 254% in Australia between 2011 and 2050 2050 (Deloitte Access Economics, 2011).

The total health and residential aged care expenditure on dementia was estimated to be $3.8 billion in 2003 and is estimated to increase, from then, to $17.8 billion in 2033. Over half of this increase is predicted to be attributable to ageing (AIHW, 2008).

Risk factors

Recognized risk factors for dementia are old age and some genetic factors, with smoking, high blood pressure, low birth weight, severe head injury and diabetes regarded as likely risk factors. Although dementia is incurable, some treatments have been shown to slow progression of the disease including medications currently available in Australia as well as improved management of conditions that are risk factors such as diabetes and high blood pressure. Increasing evidence shows the benefits of physical activity in dementia prevention with estimates that a reduction from 70% to 50% in population inactivity from 2009 to 2050 would see a 5.7% reduction in cases (Access Economics, 2009).

Early detection

Early detection of dementia is increasingly promoted as the benefits of this approach become more evident. Early detection can promote or facilitate access to treatments which may slow the progression of the disease as well as provide acknowledgement for patients and families of a reason for their problems and time for preparation and planning for the future (Manthorpe et al., 2003).

Support for carers is a key issue with approximately 30% of carers of persons with dementia found to be depressed (Schoenmakers et al., 2009). Mittelman et al, (1996) found that support for carers assists them to care for their relative for longer at home reducing the need for admission to nursing home. This is particularly the case in early and middle stages of dementia. Early detection is supported by Alzheimer’s Australia, the peak advocacy and support group for Australians living with dementia (Alzheimer’s Australia, 2010).

Delays in Diagnosis

Despite evidence of the benefits of early diagnosis, delays in diagnosis are common. Speechly et al. (2008) conducted a survey examining timeframes of dementia identification and found that family members noticed the first dementia symptoms 1.9 years before their first consultation with a health professional about dementia and 3.1 years before a definite diagnosis. Utilisation of resources to support care was found to first occur 2.8 years after the initial symptoms were noticed.

Risks of early diagnosis

There are risks with early detection. For the patient there may be isolation, embarrassment and confusion and families may be unprepared for changes that may be required (Iliffe and Manthorpe, 2004). Intra family conflict may arise (Hansen et al., 2008). Iliffe et al. (2003), highlight that there are difficulties in accepting a diagnosis for health professionals as well as for patient and families.

Risk versus benefit

Data drawn from a series of multidisciplinary educational workshops in the UK found health practitioners agreed on the risks of isolation, stigma, shame and anxiety for patients and families but could also see benefits in early diagnosis particularly for families (Iliffe et al., 2003). This creates a potential catch 22 for GPs who are aware of the problem but reluctant to begin a process of identification because of the problems it may raise for patients and carers.

Iliffe and Manthorpe argue that there is an emerging “shift from a patriarchal to a more autonomous model of health” (2004:p99). This is supported by evidence that patients appear to want early diagnosis (Jha et al, 2001). There is a need for greater capacity within the primary care sector to respond to the challenges of early diagnosis of dementia including addressing the issue of Primary Care Practitioner risk aversion, (Iliffe and Manthorpe, 2004). Wilkinson and Milne (2003) argue there is a need to develop a role for patients in improving diagnosis based on exploring the patient perspective - an area that has largely been neglected. Alzheimer’s Australia advocates improved responsiveness to patients presenting with cognitive impairment by Primary Care Practitioners particularly General Practitioners (GPs) and Practice Nurses (PNs) (Alzheimer’s Australia, 2010).

Identification of dementia

A range of dementia screening tools have been developed for use by Primary Care Practitioners to facilitate detection in the primary care setting. The most common of these are: the Mini Mental State Examination (MMSE), (Folstein et al., 1975); General Practitioner Cognition Tool (GPCOG), (Brodaty et al., 2002); and Rowland Universal Dementia Assessment Scale (RUDAS), (Storey et al., 2004). The key characteristics of a dementia screening tool for use in the primary care setting identified by Culverwell et al., (2008) are that it is short; cheap; acceptable for clients and health practitioners; easy to deliver, including scoring and interpretation; and that it has been validated. These are not diagnostic tools but screening tools that aim to provide an indication of whether a patient requires further investigation in which case they may be referred to specialist memory assessment services (Culverwell et al., 2008).

Diagnosis by General Practitioners

GPs have been found by Olafsdottir et al. (2000) to underestimate the occurrence of dementia. Boustani et al. (2003) found GPs miss approximately 50% of dementia cases. These findings are supported by current research by Pond et al., (NHMRC 351220), where GPs identified less than 50% of patients subsequently diagnosed with dementia by research nurses using the Cambridge Cognition Assessment (CAMCOG).

Apart from the risks related to dementia detection identified above, there are a range of other reasons why rates of diagnosis of dementia in General Practice are low. Renshaw et al., (2001) found that in the UK only half of the GPs who responded to a survey felt that early detection and diagnosis of dementia was important and many others were uncertain. A similar picture emerges in Australia where early detection of dementia is seen as not overly important and perhaps even as harmful (Hansen et al., 2008). This skepticism around diagnosing dementia is also highlighted by Iliffe and Manthorpe (2004) and may be related to other factors which may raise doubt and lower GPs' confidence in identifying a cognitive problem.

Examples of these factors are lack of time, confusion regarding the value of screening tools and the ethics of using them, a factor identified as a barrier to their use (Iliffe et al., 2003; Turner et al., 2004). GP's have also shown uncertainty about diagnostic processes and limited knowledge of diagnostic services as well as low levels of confidence in their own capacity for diagnosing dementia (Iliffe and Manthorpe, 2004; Turner et al., 2004). It has been suggested that negative attitudes to screening need to be overcome before screening for dementia can be more widely accepted (Iliffe et al., 2003). Indeed screening in isolation without appropriate follow up diagnostic assessment may not be acceptable or indeed useful in general practice.

A perceived lack of availability of dementia care services on the part of GPs has also been found to be a barrier to diagnosis. This is supported by research showing that GPs are more likely to pursue a diagnosis if they see benefits for the patient; for example where making a diagnosis facilitates access to specific services (Hansen et al., 2008). GPs have been found to regard dementia care to be more the role of a specialist medical practitioner than the role of a GP (Turner et al., 2004). Evidence also suggests that GPs are skeptical about the benefits of dementia medication which may also influence willingness to make a diagnosis (Hansen et al., 2008).

Need for new approaches to dementia care

Evidence is accumulating on the need for new approaches in service delivery for dementia care. Interviews conducted by Pratt et al (2006) with a range of health professionals in the UK highlighted the need for more broad ranging models of care which take into account the wider social context in which dementia care services are delivered and not just individual factors. This is supported by Bree and Meldrum (2005) again in the UK, who emphasize the need for more collaborative models of care along the lines of the chronic disease collaborative care models. The need for improved referral pathways for dementia diagnosis and care has also been identified by DeLepeleire et al. (2008).

The Nurse role

The nurse role in primary care is the fastest growing area of health care and the concept of GP and nurse collaborative care is widely supported (Watts et al., 2004).

Trickey et al. (1999) identified the 75+ health assessment as a time where the opportunity presents for nurses to conduct screening for dementia with patients aged 75 years and over and she investigated how well nurses assess and manage patients with symptoms of memory loss. She found significant variation in the use of dementia screening tools and management of patients with memory loss suggesting a somewhat haphazard approach. Trickey et al. (1999) suggest nurses are not well equipped to assess patients and that a perceived lack of autonomy among practice nurses means they feel unable to take a more active role in management of the patients presenting with symptoms.

Sibbald however, (2006) believes nurses already have a key role in complementing the role of GPs in the primary care setting and that extending their role is seen as a suitable strategy for enhancing service capacity. Practice nurses themselves see their role in the future as working in close collaboration with GPs and other health care practitioners, further developing their capacity to support improved patient care (Watts et al., 2004)

Summary

The increasing prevalence of dementia in Australia presents a significant challenge. Early diagnosis is regarded as desirable by a range of experts. The role of Primary Care Practitioners in early detection and management of dementia is widely acknowledged. Lack of knowledge, training and skills for diagnosis as well as lack of awareness of available diagnostic and dementia support services and treatments are seen as key barriers influencing the low rates of dementia diagnosis by GPs. The potential impact on the GP patient relationship is also an important factor.

Growing interest in expanding the role of nurses in primary care and an increased focus on multi-disciplinary care, together with growing demands on the health sector for dementia care services, provide the opportunity for exploration of new models of care. One such model would involve greater practice nurse involvement the detection and management of dementia in the primary care setting.

Aim of this study

To develop, implement and evaluate a nurse led model of dementia screening and assessment in general practice to support general practitioners in early the diagnosis of dementia.

Research Question

What are the key factors (barriers and drivers) that influence the implementation of the nurse led dementia screening and assessment model?

Objectives

- To explore factors that support and inhibit implementation of this model of care in the general practice setting.
- To make recommendations for modification of the model to improve capacity for further development and implementation.

Methods

A participatory action research (PAR) approach was employed for this project to support development of a model of care that would be practicable and applicable for the complex and varied service delivery environment of Australian general practice.

Recruitment of General Practices and Primary Care Practitioners

Beginning in late 2009 a convenience sample of 2 large multidisciplinary general practices located on the Central Coast of New South Wales was identified. These 2 practices comprised a small pilot study with which to begin exploring the model of care. Subsequently a few months later a further 4 practices were identified and recruited to the study bringing the total to 6 practices. Letters of invitation were sent to each of the practice principles inviting them to participate in a trial of a model of nurse led dementia screening and assessment in general practice. This letter was followed up by a phone call to arrange a meeting where practice staff then met with the Chief Investigator and the Project Officer to discuss the project and gain the consent of the participating Practice Principles, Practice Managers, GPs and Practice Nurses. Staff not present on the day, were provided with the same information and their participation and consent gained at subsequent meetings.

Development of the model of care

During the first practice meetings, possible components of a proposed model of care (Appendix 1) were proposed to practice staff who agreed on a draft model of dementia detection and care planning.

The model of care:

The elements of the initial model included:

- addition of a brief Dementia screening tool (specifically the GPCOG) to the 75 Plus Health Assessment - a Medicare rebatable health assessment already being conducted in both practices for patients aged 75 years and over;
- recruitment and consent of eligible (Appendix 2), agreeable patients and their carer at screening;
- referral of the patient by the GP and Practice Nurse, and their carer, to a Specialist Memory Nurse (SMN) for comprehensive assessment (Appendix 3)
    - with consent, patient assessment included cognition using the CAMCOG (assessment was not progressed if this score was in the non-dementia range ie. >83) activities of daily living, quality of life and mood;
    - with consent, carer assessment included carer burden, mood and quality of life; and
- multi-disciplinary case discussion and care planning with the primary care team based on assessment findings reported by the SMN.

Patient and Carer Recruitment

Patients were recruited based on their eligibility and willingness to participate in the study with a target of 60 patients overall, 10 from each practice. This target was based on previous experience recruiting patients in general practice and was set as a challenging but realistic target which would allow sufficient recruitment to develop a workable model of care. Recruitment ceased at 58 patients in late 2011, partly due to project resource constraints but also having developed a workable model of care.

Eligibility for invitation to participate in the study was initially based on the General Practitioner Cognition (GPCOG) Score, (http://www.gpcog.com.au/), (Brodaty et al, 2002). Patients with a score of 4 or less in part one of the GPCOG, were eligible to be in the study. Patients with a score of 5-8 inclusive in part one of the GPCOG, then require part 2, the informant interview, to be completed. Those patients with a subsequent score of 3 or below in the informant section, were also eligible to be in the study.

Exclusions from this study included patients with the following conditions: Parkinson’s disease, multiple sclerosis, motor neuron disease or CNS inflammation, psychotic symptoms, developmental disability, insufficient English, progressive malignancy, substance abuse or too unwell to complete study.

In response to feedback during the pilot phase, from the first two participating practices, and in keeping with the PAR approach used, further options to support Primary Care Practitioners identifying patients with early dementia were explored by the research team with participating primary care practitioners with approval from The University of Newcastle Human Research Ethics Committee (HREC). An additional screening tool, the Rowland Universal Dementia Scale (http://www.fightdementia.org.au/understanding-dementia/rowland-universal-dementia-assessment-scale.aspx), (Storey, 2004), was introduced for patients who did not have an informant present at the time of consultation. A further recruitment option was also developed and approved by HREC, where patients could be recruited to the study, for SMN assessment, on the basis of the agreed clinical judgement of both the GP and the Practice Nurse.

It was intended at the beginning of the study that patients would become ineligible if on assessment with the Specialist Memory Nurse their Cambridge Cognition Assessment (CAMCOG) score was 81 or above as this would identify they did not have dementia. Patients with a score of 80 and below were to remain in the study and proceed to have additional assessments (see Appendix 3). This eligibility criteria was changed with approval from HREC and in consultation with participating Primary Care Practitioners as it was felt that patients and their carers would benefit from the additional assessments even in the absence of a score that would indicate the presence of dementia.

Ethics Approval

The University of Newcastle HREC approved the conduct of this research according to the study protocol. As a PAR approach was utilized a number of applications for variations to the original protocol were made to HREC and were approved. All participants were invited to participate in the study by their primary care practitioner (GP and Practice Nurse) and provided written consent. Person responsible consent was also obtained were necessary. Patients were asked to invite their carer or relative to participate and if agreeable their consent was also gained. All information from this study conforms to ethics guidelines for storage and use. The research was conducted within the scope of the HREC guidelines and The University of Newcastle Health and Safety policies.

Data Collection

Patient and carer interviews were conducted in the patient's home by the SMN, a registered nurse experienced in aged care assessment and trained specifically in implementation of the suite of assessments used in this study.

General demographic information collected from patients and their carer was date of assessment; gender; date of birth; marital status, (relationship to patient – for carer); housing status, country of birth; language spoken at home; level of education; and work status.

For patients information on the behavioural and psychological symptoms of dementia, ability to go about daily activities, depression, and quality of life information was recorded. Carers provided input to the assessment of the patient's activities of daily living and depression, as well as information on their their own coping strategies, quality of life, care burden and depression.

Data collection instruments used:

Following recruitment to the study using the brief dementia screening tools outlined previously or through the clinical judgment of the GP and Practice Nurse, the specific assessment tools conducted by the SMN were as follows:

Cognition: Cambridge Cognition (CAMCOG) section of the Cambridge Examination for mental disorders of the elderly (CAMDEX) (Roth et al. 1998). The CAMCOG is comprised of 68 questions which assess cognitive function in 7 domains: orientation, language, memory, attention/calculation, praxis, abstract thinking, and perception. A highest possible score of 105 with a cut off of 80/81 differentiating between demented and non-demented individuals, with 93% sensitivity and 87% specificity, was adopted for this study as an indicator of dementia in keeping with existing research (Huppert et al. 1996; Roth et al.1998).

Depression: To assess depression in patients the Cornell Scale for Depression in Dementia was used (Alexopoulos et al., 1988). This tool was specifically developed to assess signs and symptoms of major depression in patients with dementia where both the patient and informant provide information during a semi structured interview using 19 questions to ensure a more accurate picture of the patient's mood is gained. Each item is rated on a severity scale: 0= absent, 1=mild, 2=intermittent. A score of 19 and above indicates definite major depression. A score of 6-18 with clinical judgment may indicate mild depression. A score below 6 indicates no signs or symptoms of depression.

Depression in carers was assessed using the Beck Depression Index (Beck, 1996), a 21 item self-reported inventory. It is comprised of items relevant to symptoms of depression such as hopelessness and irritability, cognitions such as feelings of guilt or being punished and physical symptoms like weight loss, tiredness and low libido.

Activities of daily living: Patients' activities of daily living were assessed using the carer rated Bristol Activities of Daily Living (Bucks et al. 1996). This 20 item scale, developed specifically for use with people with dementia, rates activities and levels of ability considered important by carers. Activities of daily living are rated to provide an overall rating of minimal to severe level of dependence with a score of 0 being totally independent and a score of 60 being totally dependent.

Quality of life: Quality of life assessment employed the Quality of Life in Alzheimers Disease (QOL-AD) tool (Logsdon et al 2002). The assessment contains 13 items covering domains associated with physical and mental health, personal relationships, finances and overall quality of life. It is scored on a 4-point Likert score ranging from 1 (poor) to 4 (excellent) with total scores ranging from 13 to 52. Higher scores indicate better quality of life. The patient's carer also completes a QOL-AD carer version which provides additional information with the patient's scores given double the weighting of the carer scores.

For the carer, quality of life was measured using the WHOQOL-BREF (World Health Organisation 1993). This widely used tool validated for the Australian context (Murphy et al. 2000) and for patients with mild to moderate dementia (Lucas-Carrasco et al. 2011) covers four domains: physical, psychological, social relationships and environment. Scores are calculated by reversal of negative items, summing and transforming to gain a score out of 100. Higher scores represent a higher quality of life.

Coping strategies: Carer coping strategies were assessed using the Brief Cope (Carver 1997) a 28 item self-completed questionnaire designed to measure emotion focused, problem focused and dysfunctional coping strategies.

Carer burden*:* Carer burden was measured using the Zarit burden scale (Zarit et al., 1980) which was developed to measure subjective burden among caregivers of adults with dementia and is the most widely referenced scale in studies of caregiver burden. Each question is scored on a 5 point Likert scale ranging from - never to nearly always present. Total scores range from 0 (low burden) to 88 (high burden). Score values and interpretation are guidelines only.

With all assessments, responses were recorded manually on paper and then de-identified, checked for any errors in summing and transferred to an excel database.

Patients and carers were provided with an opportunity to provide feedback on their perceptions of the assessment processes through a satisfaction survey.

Evaluation

Summative and formative evaluation data were collected throughout implementation of the project both to inform development of the model and to gain feedback from key stakeholders.

The primary method of data collection involved interviews with key stakeholders. Semi structured, open ended face-to-face interviews conducted with stakeholders were audio-recorded and transcribed verbatim. A series of questions (Appendix 4) were prepared as a guide in advance. These were adapted as the interviews progressed to adjust for information already provided or to probe for further relevant details.

The following participants were invited to be interviewed if they had a role implementing any stage of the model of care or if they had organisational responsibility for development of practice protocols or human resource allocation as these were judged to be important for sustainability of the model. Interviewees were chosen in order to support the interrogation and development of the model of care.

- Practice Nurses with a role conducting 75 Plus Health Assessments
- Practice Nurses with a role in subsequent care planning
- SMNs who conducted assessments and were not part of the research team
- GPs whose patients were recruited to the study
- Practice Managers
- Practice Principals

Interviewees were aware when they were recruited to the study that they would be invited to be interviewed and were aware they could opt not to be interview. Suitable times and meeting places were arranged by phone and the option provided for review and editing. Individual interviews lasted between 45 minutes and one and a half hours long.

Interviews were conducted away from others in a quiet space usually at the practice. One group interview was conducted where it was difficult to arrange individual time with interviewees and one interview was held at the end of a case discussion as this was the only convenient time for the GP. During all interviews interviewees appeared at ease answering all questions.

The transcripts were thematically analysed and key themes identified. Information emerged that linked directly to the processes of the model of care about which specific questions were asked during interview. Other information about dementia more generally also emerged and these are integrated into the overall findings presented here.

A steering group made up of Australian and International experts in primary care and dementia research met regularly throughout the project to oversee development and implementation.

Results

As expected, slight adjustments to the model of care were required because of differences between practices in their protocols. These were minimal and related to timing of GP/patient consultations throughout the process as well as differences in 75 Plus Health Assessment practice implementation protocols at the different practices. Thus some flexibility was required to be built into the model to allow for this.

Information on recruitment to the study is presented here including numbers of health professionals who participated and were interviewed and patient/carer recruitment numbers. The themes identified through analysis of the interviews conducted are also presented. These are grouped under headings which emerged as the data was interrogated.

Recruitment results

Recruitment of health professionals to the study is outlined in Table 1. From the 6 practices enrolled in the study, 33 GPs and 14 Practice Nurses participated. Three SMN's were employed by the project to conduct the specialist patient and carer assessments. All the Practice Nurses were interviewed as they all were active participants in the study. Seventeen GPs were interviewed. Some interviews were conducted as part of the case discussion.

Table 1: Number of practice staff recruited and interviewed

Position	Number	Number Interviewed
Practice Principal	6	6
Practice Manager	6	2
GPs	33	17
Practice Nurses	14	14

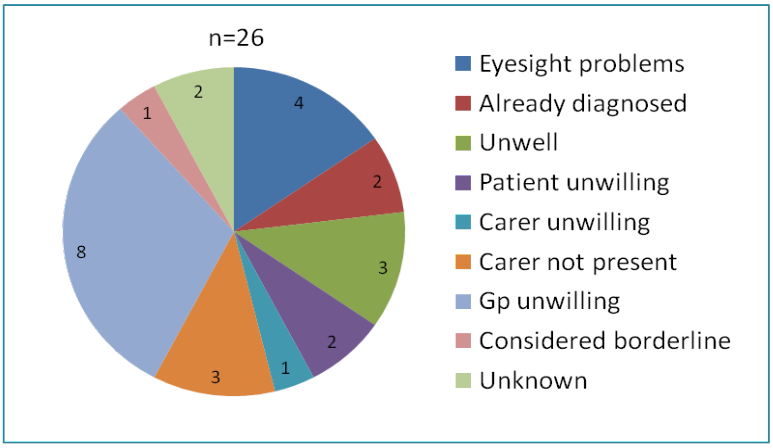
Table 2 provides information on the number of GPs recruited from each of the 6 participating practices as well as the number of recruited GPs who subsequently referred patients to the SMN for further assessment and the number of patients overall referred from each practice in the last column. This information indicates that those practices where only one GP was recruited referred more patients for further assessment. This may be because meetings with these GPs were not in a group with other GPs but one to one with the Chief Investigator (and project officer). These GPs may have had more time to have their questions answered or may have felt more responsibility to refer patients into the study as there were no other GPs to do it.

Table 2: GPs recruited by practice and number of patients recruited per GP.

Practice	Number of GPs Recruited	Number of GPs who referred patients	Number of patients referred
1	14	3	11
2	8	5	10
3	6	3	7
4	1	1	14
5 (*solo*)	1	1	11
6	3	2	5

Figure 1 outlines the reasons given by PNs, for eligible patients not being recruited to the study. These relate to mostly to patients' physical inability ie. eyesight problems or being unwell (7) and unwillingness on the part of the patient, carer or GP (11). The carer not being present to complete the GPCOG informant section and provide person responsible consent was also a significant reason given for non-participation (3). Two patients became ineligible as it was found that they had already been diagnosed with dementia.

Figure 1: Primary reason for non recruitment of eligible patients



The very low number of patient participants recruited to this study alerted us to the need to examine in more detail the barriers and enablers to implementation of this model of care in general practice. All GPs and PNs who were involved in recruiting patients to the study were therefore invited to be interviewed as outlined previously. These interview results are presented later in this report.

Participant characteristics

Characteristics of patient participants are presented in Table 3.

Table 3. Patient Characteristics

Characteristic	Dementia (CAMCOG <81) n=24	Standard Deviation	Non-Dementia (CAMCOG>80) n=20	Standard Deviation	Chi Square Value
Age (SD)					
Patient	81.6 (5.3)	5.3	80.5(4.8)	4.8	
Carer	69.3 (14.3)	14.3	77.9 (5.3)	5.3	
Gender (%)					3.13
Male	8 (33.3%)		12 (60.0%)		
Female	16 (66.7%)		8 (40.0%)		
Higher Education (%)					
University Degree or higher	0 (0.0%)		3 (15.0%)		3.73
Certificate or Diploma	2 (8.3%)		1 (5.0%)		
Trade/Apprenticeship	0 (0.0%)		1 (5.0%)		
Education (%)					18.38
High School Leaving Cert	0 (0.0%)		1 (5.0%)		
School or Intermediate Cert	4 (16.7%)		11 (55.0%)		
No School Cert or other qual.	18 (75.0%)		3 (15.0%)		
Carer present (%)	19 (79.2%)		10 (50%)		2.79

Carer Gender (%)	*n=19*		*n=10*		
Male	7 (36.8%)		3 (30.0%)		0.14
Female	12 (63.2%)		7 (70.0%)		
Basis for referral (%)					0.11
By clinical Judgement	19 (79.2%)		15 (75.0%)		
By screening	5 (20.8%)		5 (25.0%)		
Brief screening tool* **results(%)**	*n=21*		*n=11*		7.85
either as basis for referral or subsequent to referral	20 (95.2%)		6 (54.5%)		
Possible impairment	1 (4.8%)		5 (45.5%)		
No indication of impairment					
Length of Assessment in minutes (SD)					
Patient	91.2 (29.8)	29.8	76.1 (21.5)	21.5	
Carer	62.7 (22.4)	22.4	67.2 (29.8)	29.8	

*Brief screening instruments for which information was available from practices or conducted by the SMN were the GPCOG, RUDAS and MMSE. Some patients were referred based on GP and Practice Nurse Clinical judgment but subsequently has a brief screening assessment by the SMN.

Analysis

Univariate analysis only was conducted, as numbers were small. T-tests were performed to compare means, and chi-square tests were performed to compare categorical data.

A total of fifty eight patients were recruited to the study. Of these 44 patients and 29 of their carers, who agreed to participate, completed assessments with the SMN which were reported back to the GP and Practice nurse using a multidisciplinary case discussion format. Of the 14 patients who were recruited but did not have reports returned to the GP and Practice Nurse; 2 assessments that were conducted did not result in a written report for the practice as a SMN was unable to complete these; 1 patient was dysphasic and unable to complete assessments; 1 patient lived remotely and access prevented conduct of the assessment; 5 patients were unwell or admitted to care; 1 patient was referred to the geriatrician and diagnosed with dementia; 1 patient was unable to be contacted; and 3 patients subsequently declined to be participate with no reason given.

The study population is small however the results in table 3 above indicate that patients whose CAMCOG assessment placed them in the dementia group were less likely to have school qualifications group that did not score in the impaired range ($p<0.001$). Brief screening tool results were significantly different in the expected direction of showing more impairment in the dementia group ($p=0.005$).

Out of 44 patients referred for SMN assessment, 19 in the dementia group and 15 in the non-dementia group were referred on the basis of the clinical judgment of the GP and PN than by the use of a brief dementia screening tool . Of those referred on the basis of the result of a brief screening tool, 5 were subsequently within the dementia range on CAMCOG assessment and 5 were not.

Table 4 outlines the patient and carer assessment results.

Table 4: Patient and carer assessment variables

Patient Assessments	**Dementia (CAMCOG<81) n=24**			**Non-dementia (CAMCOG>80) n=20**			
	Mean	Standard Deviation	**Range**	Mean	Standard Deviation	**Range**	**P-Values**
CAMCOG (*out of*)							
Orientation (10)	6.5	2.7	**0.0-10.0**	9.3	0.8	**8.0-10.0**	3.20
Language (30)	21.5	2.9	**14.0-27.0**	25.6	1.1	**24.0-28.0**	8.44
Memory (27)	12.5	5.0	**0.0-22.0**	20.2	2.9	**15.0-24.0**	2.75
Attention –calculation (9)	4.0	2.4r	**0.0-9.0**	7.6	1.6	**4.0-9.0**	5.63
Praxis (12)	8.8	1.9	**4.0-11.0**	10.2	1.7	**7.0-12.0**	0.01
Abstract thinking (8)	3.8	1.9	**0.0-7.0**	6.4	1.3	**3.0-8.0**	5.18
Perception (9)	5.7	2.1	**2.0-8.0**	7.4	1.5	**4.0-9.0**	0.004
TOTAL SCORE (105)	62.8	12.6	**31.0-80.0**	86.5	4.1	**80.0-94.0**	1.48
Cornell depression scale	7.6	4.8	**0.0-20.0**	6.7	5.1	**0.0-19.0**	**0.56**
Bristol activities of daily living	10.9	6.4	**0.0-22.0**	8.9	9.4	**0.0-27.0**	**0.58**
Quality of life – AD							
Patient	33.2	5.5	**19.0-42.0**	36.7	6.2	**26.0-49.0**	**0.06**
Carer	27.9	7.3	**16.0-41.0**	35.3	4.6	**27.0-43.0**	**0.003**

Carer Assessments							
Beck's depression scale	7.1	6.2	**2.0-19.0**	9.5	5.1	**2.0-16.0**	**0.33**
Brief Cope	47.6	19.6	**1.0-79.0**	49.3	16.6	**28.0-82.0**	**0.82**
Zarit burden	19.6	16.5	**0.0-46.0**	21.8	15.5	**5.0-48.0**	**0.75**
WHOQOL BREF							
Overall QOL	3.8	1.0	**2.0-5.0**	4.1	0.8	**3.0-5.0**	**0.34**
Overall Health Satisfaction	3.9	0.7	**3.0-5.0**	3.4	1.4	**1.0-5.0**	**0.35**
Physical	57.4	10.7	**28.6-71.4**	55.4	6.9	**46.4-67.9**	**0.58**
Psychological	65.2	14.3	**45.8-87.5**	66.1	10.1	**50.0-79.2**	**0.85**
Social	56.4	21.4	**16.7-100.0**	61.5	29.5	**0.0-100.0**	**0.67**
Environmental	78.3	13.0	**59.4-100.0**	77.3	15.7	**62.5-100.0**	**0.88**

Patient assessment results

Twenty four patients, out of a total of 44 patients assessed, were found to be within the dementia range on CAMCOG assessment. Two domains were found to be statistically significant on t-test, praxis (p=0.01) and perception (p=0.004). The highest score in both the dementia in non-dementia groups was 94 out of 105 which indicates that all patients referred into this study did show some degree of cognitive impairment on CAMCOG assessment. Although only those who scored below 81 would be considered to have dementia all of these patients in the non-dementia group require follow up assessment.

Patients in the dementia group on average scored slightly higher on the Cornell Depression Scale, with a higher score on this scale indicating more severe depression. Both groups scored more than 6, below which indicates the absence of depressive symptoms. This was not statistically significant (p=0.56).

Patients in the dementia group also scored higher on the Bristol Activities of daily living scale with higher scores indicating increased difficulty in completing tasks of daily living. Those in the non-dementia group had a mean score of 8.9 compared to those in the dementia group of 10.9. It appears patients in the non-dementia group are also somewhat impaired in their functional ability around the home and this most likely relates closely to the mild cognitive impairment evident from the mean CAMCOG score mentioned earlier.

Quality of life for patients in the non-dementia group was higher (mean 36.7) than for patients in the dementia group (mean 33.2). This was not statistically significant (p=0.06). Quality of life of patients as described by the carers for those in the non-dementia group was higher (mean 35.3) than for patients (as described by their carer) in the dementia group (mean 27.9). This was statistically significant (p=0.003).

Carer assessment results

Perhaps due to small numbers, there were no significant differences between carers of people who scored in the dementia range and carers of those who did not score in the dementia range. However, it should be noted that there was a relatively high degree of carer burden amongst those who cared for people with cognitive impairment not meeting criteria for dementia.

Patient and Carer satisfaction survey results

Patient and carer satisfaction surveys (Appendix 5) were distributed to all patient and carer participants. The results are outlined in table 5.

Table 5: Patient and carer satisfaction survey

		Patients n=33	Carers N=21
Was the length of assessment acceptable?			
	YES	29	19
	NO	4	2
How useful did you find the interview with the nurse?			
	Very Useful	17	12
	Somewhat useful	10	7
	Uncertain	4	1
	Not very useful	0	1
	No use at all	1	0
Would you recommend this interview process to others?		(n=32)	(n=20)
	YES	29	19
	NO	3	1
How did you find the examination?	Liked it a lot	22	14
	Liked it a bit	6	4
	Neither liked or disliked it	4	3
	Disliked it a bit	1	0
	Disliked it a lot	0	0
	Unsure	0	0
How did you feel about the nurse and doctor checking your memory and concentration? Very reassured		15	n/a
	Reassured	11	n/a
	Neutral	6	n/a
	Irritated	0	n/a

	Very irritated	0	n/a
	Unsure	1	n/a
How did you feel about the nurse and doctor asking you questions about your role as a carer?			(n=20)
Very reassured		n/a	11
	Reassured	n/a	8
	Neutral	n/a	1
	Irritated	n/a	0
	Very irritated	n/a	0
	Unsure	n/a	0

Overall patients and carers were very satisfied with the processes of the assessment with 29 out of 33 patients and 19 out of 21 carers being happy with the length of the assessment. Twenty six out of 33 patients were either reassured or very reassured by the assessment and 19 out of 20 carers were very reassured or reassured about the nurse and doctor asking questions about their role as a carer.

Semi Structured interview results

Perceptions of early detection of dementia

Interviewees generally were positive about early detection recognising it as beneficial: *“Oh yes, yes, cause the family suffer... absolutely I see the benefit of picking this up”* (PN5). One SMN commented “*absolutely, identifying people with problems early has got to be the biggest single thing*” (SMN2).

One GP seemed unsure of the benefits in some circumstances: *“as a GP you may not avoid the diagnosis of dementia but avoid the intense exploration of it because you know that that person will not leave their home and will not access services*” GP2.

Maintaining a good relationship with the patient is important and so a progressive approach is more desirable: *“you have your list of things you can do... you can tick* *them off progressively as that probably would be the way to do it ... what you are trying to do is maintain a relationship … you don't want to belt them around the head every time they come in*" GP2. A systematic but relatively simple approach is what this GP proposed.

Early intervention is considered beneficial "*because earlier intervention would be so much better than waiting until they're elderly and even more frail*" (PN8). An SMN felt it is "fabulous that people are being assessed early so they can get help they need" (SMN2).

Early intervention would give the "*family more time to be a little bit more aware of things rather than things getting into a crisis situation*, …*empowers families (and) gives them a process"* (PN8). It provides an opportunity to get stuff started .. she may not need them (services) now but if the assessments are done and things are hovering in the background before the wheels fall off we can get stuff started for her" (SMN2).

Modifications to the model as a result of this feedback

The patient with early signs of dementia is the primary focus of this project. The project will continue to develop in the future to streamline this process. Preserving patient dignity and maintaining respect throughout the process is central and the issue of person centred care will be explored more fully in the Nurse Practitioner study which will follow on from this one.

The research team provided training to health professionals enrolled in the study in the form of the Dementia Assistance Program, a training program developed in Western Australia (Canning Division of General Practice, 2008). This training and support provided at meetings by the research team were designed to increase skills and awareness of early detection of dementia.

Enrolment of patients in the study

Although a large number of health professionals enrolled in this study, the number of patients recruited during the pilot study was low. This was described as "*frustrating that it is taking so long*" (PN3) and "*feels like we are going in circles*" (GP1).

Interviews with health professionals participating in the project highlighted a number of reasons for this including the need for the carer to be present at screening both for implementation of the GPCOG (discussed above) and to gain patient, person responsible and carer consent: *"it all falls into place nicely if you've got the person there and their carer...because they're usually quite aware already... something that's not quite right...so they're quite happy to .. sign up..then you've got others.. there's no carer, no one to sign off anything but these people I think are the ones that need the help the most"* (PN4). Early recruitment to the study was significantly impacted on for this reason.

The consent process was considered very time *consuming "one of my biggest issues is not the GPCOGs, it's the consent"* (PN5). In one case, reimbursement from the practice for the nurse to conduct the 75 Plus Health Assessment was per patient rather than per hour worked so it was felt that there was an incentive to keep the assessments brief and a reluctance to add extra time for screening and consent for the project: *"it's a time factor basically"* (PN5). The paperwork involved felt overwhelming for PNs: *"I got it confused and I had the wrong bits of paper... so I had them all in piles but there was so many bits of paper... this is the biggest issue really"* (PN5). It was suggested it would be much easier to recruit within the practice rather than have the contract nurse try to do it in the community, particularly as very often the carer is not present. The project provided a small amount of financial reimbursement for recruitment but was minimal and did not seem to be an incentive.

Some GPs simply did not wish their patients to be referred for further assessment. One PN commented on the GPs reluctance: "*Dr X wouldn't do it*" (ie. refer the patient for assessment)", as *"what's the patient getting out of it"* (PN4).

A practice manager (PM2) commented that the word 'assessment' was putting some people off the SMN assessment as people do not want assessment as it implies they might be for nursing home placement.

Later in the study with commencement of a referral system, enrolment picked up and on PN commented "*word gets around town…they'd say such and such has been into my home and it gets passed down*" (PN7). Another PN said "*there have been people asking for it*" (PN8).

Modification to the model as a result of this feedback

The Rowland Universal Dementia Assessment (RUDAS) tool was introduced with ethics approval as an option to the GPCOG in order to provide a screening option for patients who did not have a carer with them as the GPCOG requires an informant section to be completed if the patient scores poorly in the first section. Practice Nurses advised the research team that commonly the carer is not present. Given that the Mini Mental State examination is under copyright so was not an option for the research project to use the research team offered practices the RUDAS to provide an alternative.

The paperwork was streamlined and kept to the minimum approved by ethics. Colour coded packages of paperwork were introduced for the various consent forms and information sheets in order to make the process easier for the PNs.

The option of referral based on the clinical judgment of the GP and PN eventually became the preferred method of referral for assessment as opposed to screening.

Human resource issues

Time pressures are a key issue raised in this study. A shortage of GPs means extra pressure on all staff: *"there's a huge amount of pressure on now with the lack of GPs... and that's pressure on the staff, on the nurses, on everyone... it'll be much better when we get a few more (GPs)*" (GP1). Patients are therefore more likely to talk to the nurses *"a lot of the time they will bring it up with (the PN).. rather than bring it up with the doctor... cause they're so busy.. you've only got ten minutes or so"*(PN1).

Interviewees suggest that the introduction of a new nurse led model of detection and management of dementia is easier when the PN is employed by the practice to conduct the 75 plus Health Assessment. Otherwise there is a perception that the practice does not have the same authority to delegate tasks: "*we can't sort of say .... you've got to get out and do this because (the PN) doesn't actually work for us"*

(PN1). Also: *"it would be easier having someone... doing it in the practice rather than trying to send it out... because the doctor might recognise a patient in here and they could just send them to (the nurse)"* (PN1). Screening for dementia does take extra time added to the 75 Plus Health Assessment. Practices were keen however to find solutions to these sorts of barriers. A Practice Manager found a way around the problem "*I've found some other people to help her at occasion when she's been a bit overwhelmed"* (PM1).

Also a group of Practice Nurses agreed their existing communication with the nurse conducting health assessments outside of the practice could be used to start a type of informal referral system between themselves: *"we could ask X (nurse) to sort of flag anybody that she thinks…cause she and I communicate regularly … she could just do that much, its just saying 'when you see Mrs Blogs you know see if she thinks a suitable candidate for this, call her a bit and chat to her' ".* (PN2)

Modification to the model as a result of this feedback

The option of referral of patients based on the agreed clinical judgment of the GP and PN was introduced with ethics approval. This was as a result of feedback from practice staff that time restrictions were an issue for both GPs and PNs. The introduction of this option increased the referral rate significantly. Discussions with practice staff about their own existing internal informal referral systems and discussions between practice nurses about patients requiring further assessment was integral to the development of this method of referral based on clinical judgment. The option of clinical judgment reduced the potential for a perceived increase in workload as it reduced the time taken to have patients assessed. This referral method was popular with GPs: "*It was easy, it was a form that we had to fill in so that keeps it simple…not a lot of unnecessary paperwork*" (GP3) and with PNs "*I find the referral system easy*" (PN8).

Identifying dementia – knowledge, skills and time

The health professionals who conduct the 75 Plus Health Assessment feel they do not always have the knowledge and skills to conduct dementia screening. One PN felt that the staff conducting the 75 Plus Health Assessment were not comfortable with delivering a brief screening tool, "*there's only the one who's been able to manage that... one is studying and it's probably too much for her and one probably wouldn't cope.. they're more or less technicians... they don't have a lot of background knowledge as to why they're doing these things.. they cope with what they're doing but I need to constantly support them*" (PN5)

It is felt that extra training is required to screen for dementia which is an added cost both in time and resources. This was a difficulty for one practice: “*I think part of it is her business hasn’t been running for all that long so she’s trying to set up a business and do something that takes extra time... she needs to train staff to do that*”. The PN when asked how she felt about introducing the GPCOG said “*stressed*” (PN 5). Previously the short version of the MMSE had been used as “*the long one just took too long*” (PN5).

The PN is often familiar with the patients and so is ideally placed to identify patients who may benefit from further assessment: “*Dr X actually has a lady she’s concerned that she’s got dementia.... she could be screened”* (PN2).

Given the difficulties with screening it was not surprising that discussions led to the proposal of a type of referral system. It was also not surprising as referral is such a common pathway in general practice. This project did not look into the detail of how GPs and PNs decide which patients to refer for assessment.

There was agreement among practice staff that identification of dementia should not be just for the 75 years and over population. This study used the 75 Plus Health Assessment as an opportunity to recruit participants who needed assessment for the study however participants interviewed recognized that dementia starts much earlier and were keen to have younger patients included in the study.

Some reluctance to refer to geriatricians was identified in this study. One GP was reluctant to refer to a geriatrician because the patient might be prescribed medication and the GP felt there were “*lots of side effects of medication*”, (GP4).

Modification to the model as a result of this feedback

Again training and support are integral to PNs screening for dementia. In a way the referral system bypassed this problem. The introduction of the referral system although on the premise of providing an option in the absence of the carer being present to complete the GPCOG and in view of time constraints, also facilitated the process of progressing action, when needed, on this health issue and therefore made further investigation an easy option to take without the complications of screening. Given that the further assessment included a range of functional and other assessments other than cognitive provided added impetus to this option as it meant services might be able to be accessed.

The Nurse Practitioner Study to follow on from this study will have an eligibility criteria of 65 years and over.

Communication and the general practice environment

Staff at the practices were enthusiastic about being involved in the research project and trialing this new model of care. This was particularly evident during discussions where they were keen to problem solve and discuss how things might work: "*so maybe we could bring C. (the practice manager) into that, do some sort of PDSA*" and "*maybe there is a better way for her (the other PN) to do it"* (PN1).

Despite the interest a lack of communication was evident where one PN was unaware of what arrangements were being made to enrol the practice in the study and the implications for her role in implementing the 75 Plus Health Assessments. "*I just went in blind, I had no concept of what was going on"* (PN5).

There was also a sense of disempowerment where one PN wanted to put up some information for patients but: "*I suppose I don't sort of have a wall of my own that I could stick things"* (PN2). A certain lack of autonomy and frustration is also evident "*all I can do is suggest…. I can suggest to the carer, I can suggest to patient or the doctor you know*…" (PN4).

Most PNs felt that there were easy avenues of communication between them where PNs could discuss between themselves, patients who might benefit from SMN assessment: " *I mean we could ask X (PN) to sort of flag anybody... cause she and I communicate regularly*" (PN2).

Communication between the PN and the GPs is more problematic. GPs are very busy and PNs often rely on written communication from GPs for example in the patient's notes. Reports can arrive back at the practice and the nurse "*can give the doctor the information X (the SMN) brought back and yeah it just sits there in a heap*" (PN4). Again this reflects frustration and an inability to action recommendations, even social, in a report without the GP's endorsement. This communication issue possibly reflects hierarchical management models in some practices: "*we're just nurses whereas they're still the doctor" "You go and say it to one of the other nurses or the admin staff or the admin manager but you don't always want to say (it) to the*

GP” (PN5); *“if the doctors want us to do it we have to do it”* (PM1). GPs do however appreciate the knowledge and skills that PNs do have: “*sometimes in General Practice we get lazy so it is good to have someone like X (PN) who knows the services* (GP2) and the PN “*knows lots of things that I don’t”* (GP3).

Modification to the model as a result of this feedback

The case discussion part of the model provides an excellent opportunity for multi-disciplinary discussion and management planning. PNs did not always appear comfortable attending case discussions with the GPs but almost always provided information that was not previously known to the GP. The dynamics of multi-disciplinary teams was not the focus of this study but may be examined in more detail in our extension of the study.

Practice systems

Computer technology is seen as a factor that can support the introduction of new systems of care. When asked about introducing the new dementia screening tool the Education Officer at one practice had already initiated plans to introduce the tool into Best Practice: *“ I’m trying to get Best Practice to put that into their templates for us”* (PN3). This is not always easy and the difficulties of introducing changes to protocols is highlighted “*I just sent the whole thing to them and said can you please put this in but how long that takes is you know, how long is a piece of string*”(PN3).

Staff at the practices were enthusiastic about being involved in the research project and trialing this new model of care. This was particularly evident during discussions where they were keen to problem solve and discuss how things might work: “so maybe we could bring C. (the practice manager) into that, do some sort of PDSA” and “maybe there is a better way for her (the other PN) to do it” (PN1). Despite the interest there was also a sense of disempowerment where the one PN wanted to put up some information for patients but: “I suppose I don’t sort of have a wall of my own that I could stick things”.

Modification to the model as a result of this feedback

Practices vary in their computer capacity and ability to integrate new approaches. The research team are considering IT modifications for any further development of the study. In order to improve GP attention to the reports a short summary page was inserted at the front which meant they did not have to read the whole report.

Family and carer involvement in the process

Patients can be very isolated *“unless it’s an absolute emergency and that’s the sort of situation they’re in, they haven’t had any children, they don’t socialize a lot and all they’ve got is their neighbours but don’t bother them”* (PN4). Some patients have little contact with their relative “*they sometimes don’t see their relative all that often, maybe its only Christmas and New Year …they think, ‘there’s something going on but it’s ok’… but we (at the Practice) see them all the time and we know that they’re changing”* (PN8).

This can feel like a heavy responsibility for the PN: “*so you know it puts you in a difficult situation that they’re not going to get seen to*” (PN4).

Patients are sometimes confused about their arrangements: “*sometimes the poor old darlings don’t know that they’ve got to see me even though the letter says so, so they just go in and see (the GP)*” (PN2).

Involvement of the family and carer in the detection and care of dementia is seen as very important by interviewees in this study. Some interviewees in this study felt the family the most likely people to detect the first signs of dementia. This is well supported in the literature. Both GPs and PNs comment on this: “*a lot of the time I think it will be the relatives that tell us”* (GP1) and “*I mean the family will quite often pick these things up*”, which is qualified by adding “*but they won’t say*” (PN1) or *“they want to talk to you while mum’s not in the room… I just thought I’d let you know she’s been doing this even though she will deny that sort of thing”* (PN1).

However family or a carer are not always present or available. The requirement of the informant to be present for the GPCOG is problematic for patients whose carer is not present. These patients were unable to be enrolled into this study in the initial stages as informant input was required to provide the GPCOG score and thus eligibility. A PN commented *“it’s just frustrating that you know the people that need help the most can’t get into the program*” (PN4).

Practice Nurses in this study suggested that when the 75 Plus Health Assessment is conducted in a patient’s home their carer is often not present but when patients are assessed in the practice the carer is usually present as they provide the transport. This is important to note for development of this model of care in order to ensure carer involvement.

The importance of carer and/or family involvement and communication was highlighted. One GP felt that the patient is unlikely to tell the carer what management decisions had been made at an appointment: *" carer must be present at.. specialist or any sort of other major ..appointments because if she's (relative) not going, she doesn't know what's going on and he's not likely to report what's going on"* (GP2). Also a PN:*"It needs to perhaps be stated that the carer must be present at you know specialists or any sort of other major appointments* (PN4) . Otherwise, *"if they come in…and the doctor says..this and this needs to be done, they go home in one ear out the other…whereas if they've got their family there or they've got a carer or someone to be able to support"* (PN4).

This is particularly an issue where the carer does not attend and a key decision is made such as the driver's licence is removed. In some instances this is considered to be badly handled: "*he (geriatrician) just says out you've got dementia, there goes your licence*" and "*he (the patient) really didn't like how he dealt with him…he felt degraded"* (PN 4). However *"sometimes that approach is very useful because it gets things done"* (GP2).

Lack of involvement of the carer can mean decisions are not enacted for example, the patient continues to drive as no-one else knows the licence has been removed: *"you know everything's fine.. keep driving, I'll keep doing everything as I am, there's nothing wrong with me, he's (the specialist) has not said anything*" (PN4).

Modification to the model as a result of this feedback

Unfortunately patients enrolled in the project did not progress to the stage of a case conference. However the carer was invited in all cases to be present and to access their own assessment options. For further development of the project the aim will be to progress to case conference stage and this will promote care co-ordination with carer involvement. There was a clear focus on carer well being in this study however with extensive assessment offered to carers to determine their burden, mood and coping skills. GPs and PNs are very aware of these issues for carers.

Specialist Memory Nurse Assessment

Home assessment

The benefits of having the SMN assessment conducted in the home are highlighted: "*then you get a truer picture"* (PN2) and "*you can have a look and see what's in the fridge*" (PN1). One PN commented "*we are not always aware of what's going on at home*" and "*by having (the SMN) going out and seeing what's going on at home, obviously opens that right up and gives you the exact picture of what's going on at home"* (PN4). The SMN themselves are skilled at looking for clues as to the reality of the home situation " *I always put a scanner on cars for dings and scratches"* (SMN1). Where the patient can appear fine in a short GP consultation, there is more chance during a longer consultation at home with the nurse that difficulties will become evident: "*we (the patients) put on our best fields and we deliver and the GP, how would they know…they don't always know…so unless they get a little red flag that pops up and says ooh that's a bit unusual"* (SMN1).

GPs also saw the benefit of home assessment "*I think it's great, because we don't get to see them in their home environment. I think it's wonderful to be able to have someone go out and see how they're really living their lives"* (GP7).

Wide ranging assessment

The SMN assessment not only includes a cognitive assessment but also assessment of activities of daily living, mood and quality of life for the patient and mood, burden, coping and quality of life for the carer. This is information not readily available to the GP because "*the quality of life ADLs all come into play which is what we never have time to really get on to .. the practical nitty gritty..hows the patient coping. How's the carer coping*" (GP5).

Discussions with Practice staff highlighted that the SMN assessment in this study did not include important questions about driving, the patient's legal situation for example whether power of attorney had been appointed and advanced care directives organised.

Follow up

Also highlighted was the need for follow up assessment as many patients, although not identified as being in the dementia group did show some cognitive impairment on CAMCOG assessment or functional impairment on activities of daily living assessment. This indicates the need for monitoring. One GP "*would love to do it again in a year on the same patient...vital to say we've identified all these difficulties, (but) how is he deteriorating, how steep is the slope"* (GP5).

Challenges in assessment

The potential difficulty of conducting assessments with patients with a cognitive impairment and of maintaining respect and dignity was made clear: "*they get angry, the person with dementia gets angry, the other one (relative) will hold off because they can't speak in front of them because of respect, which is you know, you've got to preserve everyone's dignity*" (SMN1). This was reiterated by a PN *"If you go in gently look, you know to help, … or you know to make things a bit safer…. instead of taking their independence away, ripping it away, help them be involved in the decisions*" (PN4).

Carer input

PNs and SMNs agreed that there is a need for carers to have time to voice their concerns without their relative present and a need for: *"a separate interview with the carer"* (SMN1). Also carers can feel reluctant to speak up "*a lot of them are frightened to speak in front of the person they care for…I think that mood swings and arguments are a big part of when you're caring for someone with dementia…at all costs they try to prevent any nasty sort of episodes"* (SMN3).

Assessment skills

The SMN assessment clearly requires extensive skill, knowledge and experience. This is evident in the comments from GPs and PNs about the detailed content of the reports (see below).

Modification to the model as a result of this feedback

This study has highlighted how important information on the home situation is and how commonly it is not fully understood for GPs and PNs in the practice. Home assessment will continue to be central to the model. The legal issues will be added to the model for exploration in the Nurse Practitioner study. Unfortunately this project was unable to offer separate assessment at a different time for the carer but this is planned for the follow up Nurse Practitioner study.

Specialist Memory Nurse report

The report was regarded as very useful by the GPs and PNs who received it "*I find it fantastically helpful. I think it's given us a lot of good information in an area which* *can be a bit grey*"(GP5). The information provided to GPs and PNs from the assessments was very detailed and one GP acknowledged that the: "*assessments that have been done are way beyond the scope of what we can do in a consultation*" (GP3). Another GP was surprised "*certainly I learnt a few things about her that I wasn't aware of like her sleeping pattern…these subtleties are somewhat unexpected*" (GP6). The detailed information presented in the SMN report "*shed light on the patient functioning in a much more subtle way and that is helpful*" (GP6). Another GP commented "*we're busy and the kind of detail that you can capture is really helpful for people who are on the cusp of dementia"* (GP7).

The presentation of the assessment results in the report template was confusing for some "*some things I didn't understand were the numbers*" (GP1).

One GP stated that the more detailed comments about the particular individual and their circumstances provided at the end of one report was very useful and that it "*gives more depth to the information*" GP2. This suggests that the assessment scores give some indication of the picture but the SMN's observations and perceptions of the situation, provided in comments through the report, are a very valuable adjunct.

The report is seen as providing a focus for discussion for the GP and PN: "*it focuses us*" GP2. Also it provides important information on other services that the GP and PN may not be aware of, as one PN states she only has the information "*that's been given to me"* (PN4) but the SMN may have more knowledge of what is available.

One GP (GP8) stated during a case discussion that she did not have enough time to read a long report. Another GP stated that a "cut down version of the report would be good" (GP2). Going over the report with the patient was mentioned by one GP as the opportunity to look at it in more detail "what'll be helpful will be the visit of the patient following getting all this back and going over it all then" (GP1).

One PN expressed some reservations saying "we've done all this work ... now .. where are we going with it, what are we going to do , what's going to come out of this for the patient" PN4. This comment related to the PN's perceived lack of autonomy and ability to act on information as she went on to say: "cause you know I can give the doctor the information that (the SMN) has brought back and yeah it just sits there in a heap" PN4.

Although the report has been useful and the case discussion provided an opportunity to hear what the GP thought, PN's can feel disempowered "*I really can't organise anything or say anything to him (GP) all I can do is suggest. I can suggest to the carer, I can suggest to the patient or the doctor you know*" (PN4). It is felt the patient will listen to the doctor, and even "*more you know if they've had a good relationship with them*". The assessment report "*opens their (GPs) eyes up. You know then they think maybe I really should be doing something*" and "*all the hard works done really. The doctor sometimes has just got to sit back and go well here's what I need to do ...its really put down in point form for them*" (PN4).

Modification to the model as a result of this feedback

A report template was developed with a cover sheet outlining all the key assessment results. GPs indicated they had little time to read reports and so the key points were summarized on the front page. The range of results for non-dementia population from research literature was included in the report for comparison.

Multi-disciplinary case discussion

Although some GPs and PNs do sit down to formally discuss particular cases, for the most part this appears to be brief and informal. GPs and PNs indicated that the study provided good opportunities through the case discussion to discuss patient care "*probably need it because it introduces a much deeper level or way of assessing mental capacity*" (GP6). A PN commented "*it gives you more insight, gives you an opportunity to find out what the other people looking after that person, what their insight is. Quite often there are parts of the puzzle you know and parts of the puzzle that the doctor knows and that the specialist memory nurse finds out" (PN8).* Another nurse however "*didn't find it any different to the information I already had*" (PN7).

On a number of occasions key patient issues were highlighted by the PN to the GP or vice versa of which they were not previously aware. For example during one case discussion the GP mentioned that the patient was attending a men's group of which the PN was not aware. There were a number of examples of this.

The suggestion was made that it would be beneficial if the SMN attend the case discussion to directly discuss the report with the GP and PN as "someone who can introduce it" (GP6). SMN's seemed in favour of this particularly as "*I felt a bit anonymous sending it (report) back*" (SMN3). Asked specifically about what might be done better in the model one SMN reported “*going back to the doctors with your report to say that this person I’m concerned about, they need whatever*” (SMN2).

Modification to the model as a result of this feedback

For the follow on Nurse Practitioner study the Nurse Practitioner will attend the practice to discuss the report with the GP and PN.

Sustainability

Some of the practices involved in this study were interested in sustainability of the project at practice level Two practices suggested that the PNs might be able to conduct the assessments either in the practice or during home 75 plus health assessment visits. This indicated not only the value GPs and PNs found from the assessment results but a willingness to look at how the model might be implemented when the project is no longer funded. One practice currently employs a mental health nurse who they would consider taking on some of this role.

Modifications

The feasibility of a practice nurse role in the SMN assessment process will be examined in the follow up study.

Discussion

Although patient enrollment in this study was initially slow adjustments resulting in the final model of care (Appendix 6) ensured the target quota of 60 patients was almost achieved. The key factor which improved enrollment was the introduction of a referral system. Working in collaboration with the practices using a PAR approach ensured this option emerged through discussion and experience with the developing model.

Although there seems general consensus on the need for early detection of dementia, the results from this study are generally in keeping with existing literature in this area on barriers to achieving this. Time constraints for Primary Care Practitioners, and knowledge of services available for dementia care are both well recognised barriers to detection in general practice (Hansen et al., 2008; Waldemar et al, 2007).

Recruitment of practices and practice personnel to participate went smoothly however many GPs recruited did not then go on to refer their patients into the study. So although in principle they agreed to participate in effect they did not. Reasons for this have been discussed. GPs who did not recruit patients were not interviewed however it would have been interesting to explore the reasons.

Reasons provided in this study for eligible patients not being recruited highlight the need for better processes of dementia detection for patients who have eye sight problems or whose cognitive impairment may be attributed to their being unwell and therefore unable to participate.

The large number of patients who were eligible for further cognitive and functional assessment based on a screening result but who did not proceed because of unwillingness on the part of the patient, carer or GP is of concern. There is a need for further exploration of this issue. It may be that involvement in a research project was a deterrent as issues of paperwork overload were raised, however issues identified in the literature such as stigma and concern about the GP patient relationship may be a more likely cause.

The carer not being present to complete the GPCOG informant section and provide person responsible consent was a significant reason given for non-participation. The use of the referral system was easily adopted and much preferred by participating health professionals.

Identification of dementia in this study was by CAMCOG assessment where a score of 80 and under indicates the presence of dementia. In this study no patient scored over 94 out of 105 in their CAMCOG assessment. Many patients in the non-dementia group showed evidence of impairment in their activities of daily living. A decision was made early in the study to remove eligibility based on the CAMCOG score and provide the opportunity for patients who did not score within the dementia range to have the full range of assessments. This highlights a group of patients with a ‘somewhat impaired but not in the dementia range CAMCOG score’, whose mild cognitive impairment (MCI) becomes evident on assessment of activities of daily living. This highlights the complexity of dementia diagnosis and the need for comprehensive assessment like that provided in this study to identify not only cognitive but also associated functional ability. It also alerts us to the need for a range of co-ordination, and preventative care services to cater to the range of cognitive ability, from MCI to diagnosed dementia and related function in our aging population with a focus on maintaining people in their home environment.

Surprising issues of lack of capacity to act on the part of PNs came across strongly in the interviews. PNs appear to feel hamstrung when they can see situational problems from the patient and carer perspective but feel there is nothing they can do but provide information. This may be a reflection of the well recognized barriers to detection by GPs identified in the literature but it may also be that nurses simply do not have the autonomy to act independently to make decisions, even in instances where these relate to social rather than non-clinical factors. This may be an indication of a lack of a distinct co-ordination role in the PN remit. One PN suggested being able to refer to a care co-ordinator would provide a pathway for action. Some nurses did not have the training or capacity to deal with the pathway required by the project. The increasing national interest in and research into the role of the PN will provide further direction here.

Relationships developed well between the research team and the practice staff. Practices were keen to be involved in the research project and happy to make time to see the research team to discuss progress. The process developed into a participatory action research like approach which worked well to inform development of the model of care.

Multidisciplinary case discussions were regarded as valuable but do not appear to be standard practice. The issue of communication between disciplines in the team requires further investigation to determine effective methods.

Skilled SMNs have been difficult to recruit to work for this project partly because they are often employed full time elsewhere but also the rate of reimbursement was considered low. Those who have agreed to do the assessments have done so mainly they are committed to and concerned about dementia care services.

Conclusions

- A participatory action research approach was integral to development of the model.
- Practice Nurses have a heavy workload and found the screening but particularly the consent process, burdensome.
- The RUDAS was preferable to other screening tools used by many PNs and led to better recruitment as it does not require an informant.

- Case identification and direct referral to the SMN were most favoured by PNs and GPs and boosted recruitment to the study significantly.
- Results from functional assessment are considered beneficial for patients and their carers whether patients are subsequently found to score within the dementia range or not on their CAMCOG result.
- Longitudinal re-assessment and monitoring of patients is considered important and is in keeping with high number of patients scoring in the MCI range.
- GPs are extremely busy and require succinct reports and recommendations. They found the SMN role very beneficial in providing a guide for care management for patients in this study.
- The formal multi-disciplinary case discussion was a valuable tool for providing a forum for a more in depth look at patient care management. A role for the SMN in this forum would be beneficial for both the co-ordination and for the SMN’s validation as an important part of the team.
- The SMN role could be expanded to liaise directly with the multi-disciplinary team in general practice.
- A need for care co-ordination is highlighted to enhance management of patients with early dementia.

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