

Out of the Shadows

A Best Practice Community Care Program for
People Living with Dementia

Phase 1 Executive Summary

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Background and Project Overview

Dementia is a progressive and often irreversible syndrome, mainly characterized by a widespread impairment of the brain functions. Dementia affects people differently and may impact their families and carers in diverse ways (Kitwood, 2005). In the earlier stages of the syndrome, people with dementia may experience difficulties in undertaking routine chores (e.g. shopping, driving). As dementia progresses, the person may experience more difficulties in daily living activities such as self-care, bathing, and eating. The other common symptoms of dementia include memory loss, personality changes, language impairment, psychiatric symptoms such as depression and psychosis and behaviour changes such as agitation, apathy and withdrawal (Australian Institute of Health and Welfare, 2007). Dementia is more commonly found in people in later life with its prevalence doubling every five years between ages 65 to 85. The number of Australians with dementia exceeded 200,000 in 2005 (about 1.0% of the population). About one quarter of this population are living in Victoria (around 50,000 people) and the number is predicted to increase to 176,000 by 2050 (Access Economics Pty Ltd, 2005). There are 250 new cases of dementia being diagnosed each week in Victoria (Access Economics Pty Ltd, 2005).

Royal District Nursing Service (RDNS) is the oldest and largest home nursing service in Australia, founded in 1885 to provide skilled nursing to the disadvantaged living in the city of Melbourne. It is a service that over the years has changed in line with the health and care needs of the community. It has evolved into an organisation that provides evidence-based general and specialist nursing care, 24 hours a day, seven days a week. Although RDNS provides a service that is available to people across their lifespan, the majority of clients are frail older adults with approximately 70% aged over 65 years.

In 2004/2005, 7.8% of RDNS clients were recorded as having a medical diagnosis of dementia. However there has been anecdotal evidence from RDNS clinicians that there are a high proportion of clients whose condition is 'hidden' as it has been neither detected nor diagnosed. Contributory factors include the ongoing stigma attached to dementia, limited awareness of the value of early detection by healthcare providers and, from the experience of RDNS, the funding constraints that have contributed to a departure from holistic approaches resulting in productivity and task orientated approaches to care.

RDNS seeks to develop a comprehensive model of care for community nursing clients living with dementia that would enable clinicians to provide appropriate interventions and support to clients throughout the entire spectrum of the disease. Early detection would facilitate diagnosis and empower the client and their family in self management strategies. As the dementia progresses, the provision of intensive supports and professional care may be required. A palliative approach to care and family support is critical as the dementia progresses through to its end stage.

A grant from the J.O. and J.R. Wicking Trust¹ has made possible the 'Out of the Shadows' Dementia Project which is concerned with the development of a best practice community care program for people living with dementia. Although this three-year project is being managed at RDNS in Melbourne, it is being conducted within the broader health care

¹ The J.O. & J.R. Wicking Trust is a philanthropic trust managed by ANZ Trustees that seeks to achieve systematic improvements through enduring, positive impact in the areas of care of the aged, problems associated with ageing, Alzheimer's disease, and benefits for the visually impaired.

environment and community at large, as it is envisaged that the model will be transferable across nursing agencies and the communities they serve.

There are two phases to the project. The aims of the first phase are to:

1. determine the prevalence of dementia and cognitive impairment among community nursing clients and describe the characteristics of this client group; and
2. identify areas of unmet need in relation to the provision of community nursing care for people with dementia

The aims of Phase 2 of the project are to develop, implement and evaluate a best practice model of care designed to support the needs of community nursing clients with dementia, their families and carers. The results of this phase of the project will be released in 2009.

The process for achieving the objectives of Phases 1 and 2 is displayed in Figure 1.

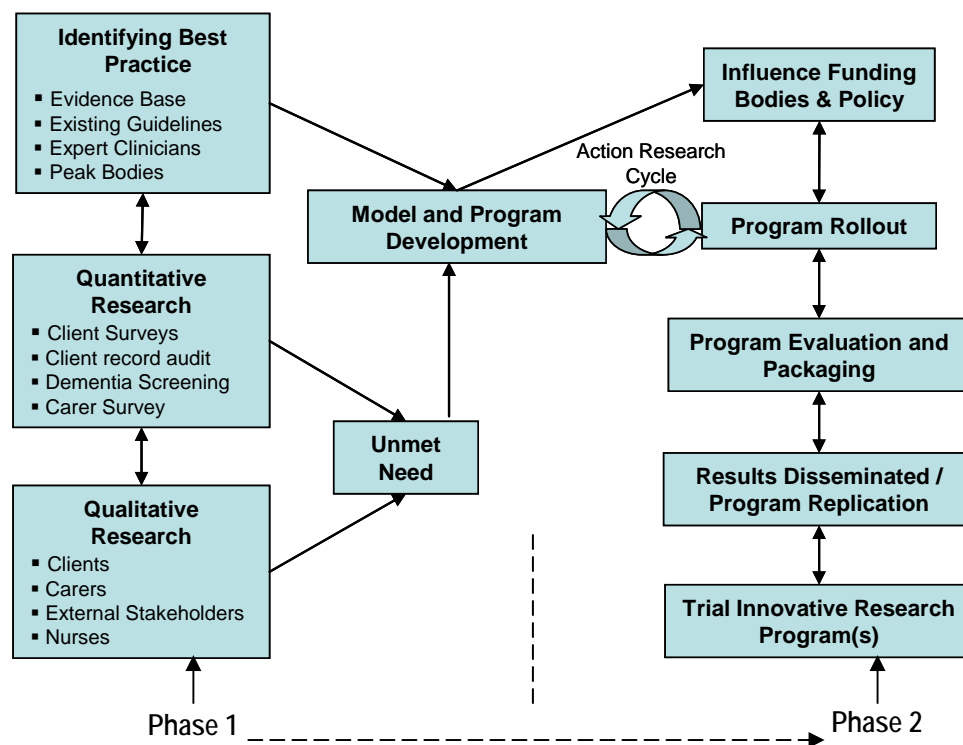


Figure 1: RDNS Best Practice Dementia Program Development

Phase 1 of the project is now complete and the findings are being disseminated in four reports which will provide a body of knowledge essential to the development of the proposed model of care. These reports are concerned with:

1. the prevalence of cognitive impairment in community nursing clients;
2. staff issues related to the provision of care to clients with a cognitive impairment;

3. issues affecting carers of community nursing clients with a cognitive impairment; and
4. an Executive Summary report which incorporates the recommendations arising from all components of Phase 1.

The present report represents the Executive Summary and comprises an outline of the main findings from Phase 1 of the project and concludes with a set of Recommendations which inform the development of the best practice community nursing model of dementia care.

Prevalence of Cognitive Impairment and Dementia

Introduction

An essential first step in the development of the dementia model of care involved the estimation of the prevalence of dementia and cognitive impairment among older community nursing clients. This was achieved by conducting a systematic survey of a sample of RDNS clients as detailed in the following section.

The specific objectives of this component of Phase 1 were to:

1. provide a profile of community nursing clients with a recorded diagnosis of dementia;
2. estimate the prevalence of cognitive impairment and dementia in community nursing clients and to describe the characteristics of this client group; and
3. conduct an audit of the client histories of a sample of community nursing clients who show signs of cognitive impairment or who have a diagnosis of dementia.

Methodology

Firstly, the RDNS Client Database (Camillus) was queried in order to describe all clients who had an ICD-9 diagnosis of dementia for the 2005/06 financial year. For the purpose of the analyses, clients with a diagnosis of Alzheimer's Disease, Arteriosclerotic Dementia, Senile Dementia, Presenile Dementia, Frontotemporal Dementia, Dementia with Lewy Bodies, Parkinsonian Dementia, Alcoholic Dementia, Drug-Induced Dementia and Senility Not Otherwise Specified were identified. In addition to diagnosis, client demographic data including age, gender, country of birth, language spoken at home, living arrangements and carer availability were extracted.

Secondly, a two-stage survey was conducted at four randomly selected RDNS centres. One RDNS centre was selected from each RDNS region (North, East, South and West) to ensure the representativeness of the sample with regard to client characteristics and the availability of health and community resources within each geographic region. The first stage of the project involved the primary nurses at the four centres completing a brief dementia checklist. The survey comprised three questions covering memory loss, confusion and diagnosis of dementia. Clients who received a positive response ("Yes" or "Possibly" to the questions on memory loss and/or confusion or "Yes" to the question on the presence of a diagnosis of dementia) progressed to the next stage of the survey.

This second stage involved a more detailed questionnaire which was completed by the client's primary nurse after consent had been obtained. This questionnaire included details of the involvement of other services in the client's care and a comprehensive functional assessment. In addition, if the client had not had a recent cognitive assessment, a Mini-

Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) was completed.

Finally, a detailed record audit was undertaken on a random selection of clients who participated in the prevalence survey. The audit covered a broad range of areas including referral information, presenting problems, medication usage, co-morbidities, carer details, nutrition, pain and driving status.

Results

The profile of RDNS clients in 2005/06 with a diagnosis of dementia found:

- Dementia is a common diagnosis among RDNS clients. In total, RDNS provided care to 30,937 clients in 2005/06 and 2,506 of these (8.1%) had a recorded diagnosis of dementia.
- Almost one fifth (19.5%) of RDNS clients with a diagnosis of dementia have a primary language other than English.
- Forty percent of RDNS clients with a diagnosis of dementia live alone and 23.2% live alone and do not have a carer.

A total of 656 RDNS clients with a mean age of 81.8 years participated in the first stage of the dementia prevalence survey at four RDNS centres. The main findings of the survey were:

- Based on the report of nursing staff, 32.6% of older RDNS clients have problems with memory loss, 29.4% exhibit signs of confusion and 22.3% have a confirmed medical diagnosis of dementia. These figures indicate very high levels of cognitive impairment among community nursing clients.

A total of 172 RDNS clients participated in the second stage of the dementia prevalence survey. This stage of the survey found:

- Only a small proportion of clients received very low scores on the MMSE indicating that the majority of clients with a cognitive impairment at RDNS are in the mild range.
- More than half (54.6%) of clients utilised informal carers.
- Among clients with a confirmed diagnosis of dementia, about one quarter (26.4%) are on Community Aged Care Packages (CACP) or Extended Aged Care at Home (EACH) packages.
- Cognitive impairment is associated with high levels of functional impairment with the most common difficulties relating to doing housework, mobility, travelling, taking medicines and handling finances.

A total of 119 client records were audited. The main results of the audit were:

- Over half of all RDNS clients with a cognitive impairment were referred for assistance with medication management (53.4%).
- There are high levels of polypharmacy in clients with a cognitive impairment with the mean number of different medications being 7.4.
- Diagnostic co-morbidities are prevalent in clients with a cognitive impairment with the most common being hypertension (62.8%), heart disease (57.5%), diabetes

- (34.5%), high cholesterol (27.4%), stroke (23.0%) and depression (22.1%).
- Almost one-quarter of clients (23.5%) with a cognitive impairment were considered by nursing staff to be nutritionally “at-risk”.
 - 40.5% of clients with a cognitive impairment were considered by nursing staff to be experiencing persistent pain.

Summary

The prevalence survey of dementia and cognitive impairment confirmed that these problems are highly prevalent among community nursing clients. The survey found that approximately one-third of older clients have memory problems and/or confusion and almost one-quarter have a diagnosis of dementia. The discrepancy between dementia diagnoses as recorded on the RDNS electronic client database and nurse report of dementia (8.1% vs. 22.3%) indicate a significant level of under-reporting of this condition and highlight the “hidden” problem of dementia within community nursing.

The high numbers of clients with a cognitive impairment from non-English speaking backgrounds highlights the need to incorporate strategies for supporting this client group within the dementia model of care. Furthermore, it was found that many clients live alone or lack the supports that a carer can provide. Strategies for engaging resident and non-resident carers and for supporting clients who lack a carer must also be a vital component of the model.

The detailed profile of clients with a cognitive impairment found that most were in the early stages of the disease and the most common reason for referral to RDNS was for assistance with medication management. As a significant number of these clients do not have a formal diagnosis of dementia, it is essential that valid screening tools are utilised to facilitate the early identification of a cognitive impairment so that clients can be linked in with appropriate services and to improve care planning.

High levels of co-morbid conditions, functional impairment, medication usage, pain, nutritional deficiencies and behavioural problems indicate that this is a particularly impaired group of clients for whom the provision of a co-ordinated best practice model of dementia care is greatly needed.

Staff Issues

Introduction

Three focus groups were conducted in September/October 2006 to identify key issues around dementia care from staff perspectives. The aim was to elicit personal impressions, beliefs and attitudes from RDNS staff about how RDNS provides care to people living with dementia, and what could be done to enhance the quality of care and support to these people.

Methodology

Managers and staff at all centres and head office were invited to participate. Five staff attended the first and second focus groups respectively and six staff attended the third focus group. Participant’s roles, focus and expertise varied and included Clinical Nurse Consultants in aged care and mental health, Clinical Coordinators, field nurses from Centres and the Homeless Persons Program, hospital liaison nurses, and nurse managers. A list of questions

to guide the three focus groups was generated following discussion amongst the Project Team members. The subsequent three audio-recordings were transcribed and a thematic analysis was undertaken to identify the main themes and sub-themes.

Results

The thematic analysis identified the following six main themes:

1. Assessment and monitoring/ongoing assessment (current roles and practices) and barriers

- Assessment of clients with dementia is often task focused, relating to the specific reason for the client's referral - often medication administration.
- Holistic assessment may be conducted for some clients.
- Some nurses monitor clients and carers in relation to safety and risk issues.
- The RDNS general assessment tool is too broad and assessment processes too time-limited, resulting in inconsistent identification of health issues related to dementia.
- Some nurses experience difficulties assessing changes which may occur for clients and their carers, for example the client's ability to safely store medications, problem solve, and changes in family circumstances.
- There may be discrepant assessment findings between Cognitive, Dementia and Memory Service (CDAMS) clinics with a neuropsychological focus, and RDNS with a nursing and functional focus.

2. Complex care provision and coordination (current roles and practices) and barriers.

- There are difficulties for clients with dementia when many different nurses visit – this interferes with the development of a consistent caring relationship.
- There is inconsistency between centres in accepting referrals for people with mental health diagnoses and cognitive impairment and the absence of relevant aged care nursing expertise and support at each centre.
- RDNS care is too task focussed at the cost of a more holistic approach due to the limited time within which nurses are required to provide care.
- There is variation among nurses' skill and knowledge.
- Some nurses consider that dementia care is not a high priority and this may result in negative outcomes as clients deteriorate.
- Care coordination and support functions are not undertaken due to requiring time outside of the client's immediate visit, which is not funded time. This includes communicating with other service providers and health professionals, both internal and external, and providing support to carers.
- Nurses assist some clients with their activities of daily living as required, in particular when clients are waiting on care packages, as an interim measure to ensure that immediate and basic health needs are met.
- There is an important nursing role of assisting to manage continence difficulties, managing crises and assisting clients and carers to negotiate the complex health and service delivery systems.
- Nurses effectively identify and manage clients considered 'at risk' using existing RDNS policies addressing 'at risk' situations and formal applications to the Victorian Civil and Administrative Tribunal.
- Nursing care is typically focused on maximising the client's independence.
- There is an important role in supporting clients and carers to remain in their own home - establishing trusting and caring professional relationships with the client and

their carer/family and undertaking supportive counselling with clients and carers/family.

- There is a need for nurses to exercise judgement of an acceptable balance between safety and risk for the client wishing to remain in their own home.
- Nurses provide health promoting education, incorporating provision of written information and sharing information regarding dementia.
- Nurses encourage carers to plan care and accept services, and assist carers to improve their management of any behavioural difficulties the client may demonstrate.
- District nurses play a central role in the team approach to care. Nurses undertake interim case management roles, although these are not recognised as such, often while clients await care packages.
- Clarification of the roles of external multidisciplinary teams is required.
- Nurses provide support and guidance to case managers in regards to dementia care.
- Difficulties in care provision are presented by challenging behaviours of clients and client/carer reluctance to accept services.
- There are an inadequate number of available culture specific care packages. Some nurses lack skill in using translators, cost and difficulty of booking of translators are barriers to their use.
- RDNS nurses effectively overcome language barriers for clients from culturally and linguistically diverse backgrounds using family to translate and professional translators.
- There is confusion for some clients when a translator is present and problems when nurses use family to translate.
- There is denial by some people from specific CALD backgrounds of care needs due to the stigma of dementia as a mental health problem.

3. Improvements to care provision

- Increased availability of Clinical Nurse Consultants in Aged Care is suggested.
- Earlier recognition of difficulties and referral would result in improved outcomes for clients.
- Nurses should be undertaking more focused functional assessments and directly observe clients preparing simple meals, dressing themselves etc.
- Use of a dementia clinical pathway is suggested.
- Nurses should be regularly re-assessing their clients who have dementia.
- Improved assessment, holistic in focus, including accurately using the MMSE, would enable nurses to better plan care, avoid crises and address palliative care needs for clients.
- All carers should be regularly screened for stress using validated tools.
- Improve collaboration with carers and with community groups such as carer groups.
- Increased availability of community care packages and carer respite.
- Better access for CALD clients to multicultural day centres and culturally specific community care packages.

4. Directions for nurse education

- Dementia focused care should be a core competency of all district nurses involved in clinical care, including accurate use and interpretation of the MMSE and how to improve care for CALD clients with effective use of interpreters.
- Dementia focused education should be provided by the RDNS Institute and at centre level, should be standardised and involve the Clinical Nurse Consultants in Aged Care

who should ideally be located in each centre.

- Education would include a substantial clinical focus - all staff would undertake visits together with the Clinical Nurse Consultant in Aged Care concerning assessment and care planning.

5. Potential limitations to and benefits of early diagnosis of dementia

- Early diagnosis could increase depression, anxiety and stress for families and carers and instil a sense of uncertainty regarding the future.
- Early diagnosis could benefit clients by enabling them to participate more fully in their own plan of care, obtaining relevant information supports and services, gain valuable current medical intervention and treatment and planning to avert crises.

6. Effective care partnerships (current practices), barriers and improvements

- Effective internal care partnerships - RDNS nurses refer to internal RDNS allied health and advanced practice nursing professionals and to external service providers and health professionals.
- Clients identified as 'at risk' are referred to the RDNS social workers in accordance with current RDNS policies and procedures for management of 'at risk' clients.
- Carers may be referred for carer support and counselling, and carers who are suspected to be experiencing cognitive impairment are referred to appropriate services for further assessment.
- There are difficulties referring to external services and in relation to RDNS receiving referrals from other providers - insufficient services to meet demand resulting in the client's needs not always being adequately addressed.
- There are long waiting periods for care packages and respite, insufficient resources including HACC services, delays in neuro-psychological assessments and resultant delayed interventions to manage clients who are 'at risk' in their own homes.
- The quality of information provided to RDNS from general practitioners is variable.
- RDNS nurses collaborate effectively with formal case managers and participate in case conferences where required.
- RDNS nurses negotiate complex health systems including initiating referrals, coordinating respite and other services (hospital and community based) and initiating placement in permanent care.
- The role of RDNS is not always well understood by external providers and also RDNS nurses do not always understand external provider's roles.
- Suggested of improvements to care partnerships include
 - improved information sharing, for example, face-to-face meetings with GPs
 - communication of assessment and review findings to partners such as Aged Care Assessment Services
 - enhanced nurse skills in running case conferences, which could be achieved via targeted education.

Summary

Overall, participants considered that RDNS dementia care meets care needs directly relating to the reason for referral to RDNS. However, it is of concern that participants were critical of the delimiting nature of 'task directed' care in that it inhibits assessment of health domains not nominated in the initial referral. This results in variable quality of care where physical, social and psychological health needs and functional difficulties may not be identified or addressed in this vulnerable and socially isolated client group.

This is of particular concern given the progressive deterioration accompanying dementia and the resultant loss of function in all areas of activities of daily living, including self-care, continence, and interpersonal functioning with carers and family, and the expected increased stress for carers and family.

According to focus group participants, the quality of care is to a large degree dependent upon the individual visiting nurse's knowledge, skill and experience with dementia, and also on the priorities determined by managers at each RDNS Centre. This highlights the absence of a standardised and holistic approach to quality dementia care.

Numerous care systems are available in the literature including clinical practice guidelines and clinical pathways. To date, development and implementation of such care systems at RDNS has been limited. Given the current variation in the quality of assessment and care provision for RDNS clients with dementia, it is timely to reconsider these approaches to care. Staff felt that a dementia-specific clinical pathway and accompanying clinical practice guidelines would be a valuable addition to current RDNS care. A clinical pathway could be a central point of reference in education for staff. Staff competencies could be built into the education package enabling a more objective process for review of nurses' skills in dementia care which could form part of the regular staff performance appraisal.

Carer Issues

Introduction

A combination of qualitative and quantitative methods identified issues affecting carers of RDNS clients with cognitive impairment. Two focus groups were conducted to explore carers' experiences and their viewpoints regarding improvements to services. A quantitative survey was conducted with 57 carers of RDNS clients identified in the prevalence survey as having signs of a cognitive impairment or a diagnosis of dementia.

Methodology – Focus Groups with Carers

Ten carers participated in two focus groups. All participants were women, fluent in English, from diverse cultural backgrounds, and living in the Melbourne Metropolitan area. Five participants cared for their spouse and the remaining five cared for a parent. A list of questions to guide the two carer focus groups was generated following discussion amongst the members of the Project Team, informed by the relevant literature regarding carer issues. The resulting two audio-recordings were transcribed and a thematic analysis was undertaken to identify the main themes and sub-themes.

Results– Focus Groups with Carers

A number of themes and sub-themes emerged from the focus group transcripts. These were collapsed into the following two main themes:

1. Access to services, barriers, and overcoming barriers

- Access to services, including accessing additional services as the person's dementia progressed, is dependent upon obtaining an accurate diagnosis.

- Barriers to access to services include inaccurate or incomplete diagnosis/es and related medical treatment difficulties, as for example a diagnosis and treatment for depression rather than identification and treatment of dementia.
- Some hospital-based health professionals ‘give up’ on the person with dementia which is a barrier to access to rehabilitation services and best practice dementia treatments and intervention.
- Some participants noted difficulty accessing district nursing care due to perceived funding issues.
- Carers emphasised the persistence required to obtain an accurate diagnosis, such as requesting GPs refer to medical specialists in dementia.
- All carer participants emphasised the persistence and resilience required to access adequate services.

2. Effective and available services, barriers, and improvements

- Care described as effective and available included
 - personal care from council workers to assist with activities of daily living
 - day centres
 - inpatient respite facilities
 - health care professionals including district nurses, medical practitioners, community aged care packages and case managers, podiatrists and physiotherapists.
- Overall, inpatient and community services are well coordinated and provide effective support to carers.
- Although carers experienced home care as somewhat intrusive, the caring attitudes of most personal care and health professional staff counteracted this.
- Importantly, participants noted that carers are the main case managers for people with dementia.
- RDNS care is described as being for wound care, pressure care, assessment and referral.
- RDNS care is described as reliable, assisting the carer to maintain the person in their own home, supportive, responsive, competent, caring, valuable and necessary.
- RDNS nurses are described as positive in their attitude towards the carer and the person with dementia. Nurses engage carers in health promotion, are knowledgeable about dementia and provide relevant education to carers.
- Barriers regarding effective services include low satisfaction with hospital care which is experienced as ineffective service provision. Dementia patients are a low priority and are not valued as ‘people’ by some hospital staff. Communication by some hospital staff is not effective, and discharge planning from hospitals is inadequate.
- Carers noted that the availability and quality of personal care varies between councils. A number of councils provide inadequate personal care and insufficient time for personal care. Some are not able to provide care at a time when carers require it.
- Some carers had negative experiences of RDNS wound care.
- Dementia patients are difficult to care for due to their behavioural problems and some health professionals have stigmatised attitudes towards them which results in ineffective care.
- Councils should be more efficient in undertaking personal care and be more responsive to requests for service in order that district nursing services are better available to undertake complex care requirements.

- GPs and other health professionals should improve communication and reliability, for example inform the carer of any changes in visit schedules, and better inform carers of available services.
- Improved discharge planning from inpatient facilities and better information provision for carers would enhance carers' ability to plan.
- Health professionals and personal carers need to improve their understanding of dementia and improve their holistic care provision centred on the care of the person.
- Respect and understanding of the person with dementia should include strong awareness that the person with dementia may not be able to communicate their symptoms and experiences adequately. This was particularly emphasised in relation to assessment and diagnostic interviews.
- Health professionals need to improve their interpersonal skills when caring for a person with dementia - talk to the person in a way that they can understand, be respectful, inform them of their plan of care, address them by their name and talk to them while standing in front of them.

Methodology – Survey of Carers

The survey sample comprised 57 carers of RDNS clients who were identified in the prevalence survey as having either a definite or possible cognitive impairment.

The survey questionnaire was developed following a review of the relevant literature and an examination of the themes identified via the focus groups with carers. The aims of the survey were to;

- describe the characteristics of carers of RDNS clients with a cognitive impairment
- assess the level of agreement between carer and nurse ratings of the client's cognitive impairment
- evaluate satisfaction levels related to the provision of care by RDNS to the client and the support RDNS nurses provide to the carer
- identify some of the negative and positive aspects of being a caregiver

The questionnaire contained the Modified Caregiver Strain Index (Thornton & Travis, 2003).

The questionnaire was delivered by post and returned anonymously. The data was entered into a Microsoft Access database and was analysed using SPSS.

Results – Survey of Carers

A total of 57 carers completed the survey questionnaire. The average age of the client was 84.9 years, 66.1% were female and 17.9% had a primary language other than English.

More than 75% of the respondents were caring for a parent and 20% cared for their spouse.

Two thirds of carers did not live with the person they care for. Among these non-resident carers, two-thirds lived more than 5km away from the client.

The carers and the nurses were each asked to rate the level of the client's memory loss, their confusion and whether or not a medical diagnosis of dementia was present.

In relation to memory loss, there was a moderate correlation between carer and nurse ratings. The correlation between carer and nurse ratings of confusion was lower. In regard to whether the client had a medical diagnosis of dementia, there was a moderate and significant correlation between carers and nurses and a moderate level of agreement. It is surprising and somewhat worrying that the level of agreement on this question was not higher.

For the 31 clients identified by the carer as having a diagnosis of dementia, the majority (61.3%) were diagnosed within the past two years and most had been diagnosed by their local GP or a CDAMS clinic.

Reasons for referral to RDNS were as follows, with some people having more than one reason for referral:

- Medication management 69%
- Wound care 25%
- Continence management 25%
- Personal hygiene 20%
- Diabetes Care 2%

Almost all respondents agreed with statements that RDNS nurses were caring, friendly, reliable and professional. Fewer agreed that RDNS nurses provide accurate information about referral and other services for clients (52%) and carers (37%).

Two thirds of respondents agreed that RDNS meets all of the nursing support needs of the person in their care. Two thirds agreed that RDNS help is easily obtainable. Two thirds felt supported and encouraged as a carer. When asked whether the nurses have a good understanding of people with memory problems, 62% of carers agreed.

Over half of respondents felt that too many different nurses visit and 44% affirmed that nurses can't say when they will arrive. 20% agreed that the nurses are too rushed.

Overall satisfaction with client care, however, was very high, with 84% of respondents indicating they were very satisfied. 72% were very satisfied with the way RDNS involved and supported carers.

Responses to the Modified Caregiver Strain Index indicated that many carers experienced high levels of stress. In particular, carers reported being upset that the person in their care had changed and that some of the person's behaviour was upsetting. Carers reported feeling completely overwhelmed sometimes (38%), or on a regular basis (28%).

Almost everyone noted that helping the person they cared for was a positive aspect of being a carer. More than half felt positive about caring for someone who had cared for them as either a parent or spouse.

Summary

Carers play a vital role in supporting the person with dementia and in assisting the nurse to provide effective care. Strategies and resources to support carers who may be under stress must be an essential component of the model of care.

Carers reported that obtaining a diagnosis of dementia was challenging. Services are accessible once an accurate diagnosis has been established, assertiveness and persistence is needed to access services which meet the particular needs of the client.

Participants felt that overall services were effective and available. However, there is low satisfaction with hospital services. Carers reported variability between personal care services offered by some councils and variation in the quality of wound and pressure care provided by some district nurses. These findings suggest that hospital, council and district nursing services may need to improve the quality of care they provide to improve care consistency, effectiveness of care and carer satisfaction in each of these domains.

Carers commented that some carers and health professionals do not value people with dementia and on the need to improve communication with people with dementia. These findings indicate that a system of care focused on holistic care provision which is also person centred may improve the quality of care for people with dementia and it may enhance the consistency of care across different locations.

The findings suggest that district nursing education should be focused on enhancing communication skills and on accurate assessment. Wherever possible, carers should be included in health assessments for people with dementia.

The dementia model of care should facilitate continuity of care and the provision of accurate information about dementia-specific resources and appropriate referral options.

Approximately one third of the surveyed carers did not live with the client and up to 20% of clients with a cognitive impairment have no carer. One of the key challenges of the model of care is to engage and support these groups.

For nurses to provide effective care, it is essential that cognitive problems are identified early and accurately. The presence of only moderate to low agreement between carers and nurses in ratings of the client's memory loss and confusion may suggest that nurses need further education and resources to enable them to better identify these problems. Furthermore, the fact that only a moderate level of agreement was observed concerning the presence or absence of an actual diagnosis of dementia may indicate that this vital information is not being relayed to RDNS at the time of referral.

Recommendations

The following recommendations for community nursing care of persons with dementia are based on the results of the Phase 1 quantitative and qualitative investigations of the RDNS 'Out of the Shadows' dementia project:

Organisational Policies and Structures

1. Community nursing organisations should give a high priority to the provision of quality dementia care. By raising the profile of dementia care and providing policies and structures to support staff, improvements in attitudes, beliefs and the dementia knowledge base will facilitate a general shift in culture within these organisations.
2. The role of community nursing organisations in relation to the identification, assessment and care of clients with dementia needs to be reviewed to ensure coordination and optimal use of dementia care services.
3. Community nursing organisations should build on current health promotion principles, introducing dementia specific chronic disease management, and education and risk reduction strategies, not only to the person with dementia but to their family.
4. Community nursing organisations should ensure that they have an adequate workforce of competent and skilled staff with advanced level dementia skills. The role of such staff is to act as a driver for quality dementia care, providing positive role modelling, information on dementia specific resources, leadership in skills development, and to work alongside nurses in a consultancy role with clients with complex or high risk needs.
5. Community nursing organisation policy should specify the circumstances under which the staff with advanced dementia skills become involved in the assessment and care planning of clients.
6. Nurses should advocate for clients awaiting community care packages which include formal case management, e.g. Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) programs, through liaison with program service providers and with Aged Care Assessment Service (ACAS), advising of changing needs, risk and urgency. Nurses should seek interim formal case management programs in cases of acute need.
7. To ensure the provision of a coordinated, client-centred and comprehensive service to the client with dementia and their family, community nursing organisations should facilitate access to a range of allied health professionals through a multidimensional approach.
8. As continuity of care is important in this client group, strategies should be developed to ensure that the number of nurses involved in the client's care is kept to a minimum.
9. Organisational strategies should be in place to enable appropriate support to clients and carers from culturally and linguistically diverse (CALD) backgrounds.

10. The specific requirements of minority groups with dementia such as younger onset dementia and people with learning disability should be accommodated.
11. To ensure the confidentiality of sensitive dementia related information, client care records are maintained in the home unless otherwise indicated following assessment. Access to the client care record is under the control of the client as indicated on the consent form.
12. Organisational performance indicators need to be developed to ensure that the model of dementia care is achieving the desired aims.

Coding and Recording of Cognitive Impairment and Dementia Diagnoses

13. Data codes should be reviewed to ensure the full range of cognitive impairment experienced by community nursing clients is captured within the service client recording system, including those with short term memory loss and mild cognitive impairment.
14. To prevent under-reporting of dementia and to facilitate referral for an early diagnosis, nursing staff should be required to record all known diagnoses of dementia, either primary or secondary, on the client database.

Assessment of Cognitive Impairment and Related Issues

15. The majority of community nursing clients with a cognitive impairment have early stage dementia or short term memory loss. The model of dementia care should emphasise early detection of dementia, however not to the exclusion of clients with more severe dementia.
16. Community nursing organisations should review their assessment processes in the context of best practice evidence for the screening, assessment and planning of care for the person with dementia, taking into account the documentation and reporting requirements of funding bodies.
17. Assessment of clients with cognitive impairment must be holistic and person-centred. Domains should include but not be restricted to; (a) risk; (b) depression; (c) delirium; (d) nutrition; (e) pain; and (f) caregiver strain.
18. A proactive risk assessment and management process should incorporate the home environment, driving, wandering, falls, dehydration and nutrition, carer stress, behaviours of concern, self neglect and abuse, medication, social isolation and unmet needs.
19. Assessment of clients with a cognitive impairment must be reviewed at regular intervals.
20. As the Mini-Mental State Examination (MMSE) only provides a rough screen for cognitive impairment in community nursing clients, who comprise mostly clients with a mild degree of impairment, it should not be used as the sole measure of cognitive

impairment. Rather, all available information should be utilised, including that obtained from other agencies.

21. Clear guidelines for the use of validated dementia screening tools should be developed in order to support clients who have concerns regarding memory loss and cognitive impairment. This will facilitate referral to general practitioners and specialist services to ensure the early diagnosis of dementia.

Management of Clients with Dementia and Cognitive Impairment

22. Advanced care planning issues should be addressed to ensure the client's maintenance of autonomy and right to self determination.
23. Appropriate supports and services should be provided to accommodate the high level of physical and psychological co-morbidities in this client group.
24. Care for the person in the later or terminal phase of dementia should be based on a palliative approach.
25. Community nursing organisations should recognise and respond appropriately to the stress and distress resulting from behaviours of concern that can be experienced by the person with dementia and their carers.
26. Nutrition-related problems impact a substantial number of clients with cognitive impairment. A best practice dementia care model in any setting should incorporate methods for identifying clients at nutritional risk and strategies for responding appropriately.
27. Planning of care should be completed in consultation with the person with dementia and their carer.
28. Community nursing organisations should identify medication risk and to respond appropriately to those who are at risk, including referral for a Home Medication Review.
29. Specialist Mental Health Nurses and other mental health services, including general practitioners, should be utilised when mental health needs are identified.
29. Nurses need to be knowledgeable of, or have access to information on specialist resources and service providers who are able to respond to the individual needs of the person with dementia. Organisations need to adopt an information sharing and collaborative approach with local service providers.
30. Community nursing organisations should aim to help streamline the transition of care of the person with dementia to external agencies via the sharing of information and reducing the duplication of assessment.

Engaging and Supporting Carers

31. Resident and non-resident carers should be offered the opportunity to be involved in care planning.
32. Carers should be consulted as to the level and types of support they are able or willing to contribute. Assumptions should not be made.
33. Support needs of the carer should be addressed. This includes access to carer support services as required, support and education, advice on caregiver interventions, recognition of the impact of caring, maintenance of the carer's health and wellbeing and support through transitions in care.

Dementia Training for Community Nursing Staff

34. Community nursing organisations should review dementia training for their staff. Key aspects should include:
 - a. Dementia training for staff should be high priority and should be mandatory.
 - b. A sufficient amount of professional development study leave should be allocated, enabling staff to undertake dementia specific education and skills development that is appropriate to their level of practice.
 - c. Each organisation should provide an adequate number of staff with advanced level dementia skills to act as a resource, a role model and as a driver for education.
 - d. Each organisation should set a minimum standard of dementia competency to provide staff access to dementia education, training and skills that provides them with the proficiency to respond to the individual needs of the client with dementia.
 - e. The staff appraisal process should be reviewed to identify and respond to nurse's dementia training needs.
 - f. Supervision should be made available to staff which values the nurse and recognises the complexity and breadth of skill required to provide quality dementia care.
 - g. Each organisation should review the availability of dementia-specific training opportunities. This should take into account flexible training delivery systems, opportunities and funding to attend internal or external courses and targeting skills development at the service delivery level utilising nurses with high level dementia skills and knowledge.

Future Research

36. Investigations are required into the experiences and needs of clients with cognitive impairment who live alone without a carer with a view to developing strategies to support their care provision.
37. A validation study is required to compare the accuracy of the Home and Community Care (HACC) Minimum Dataset cognitive impairment item with other established measures of cognitive impairment (e.g. MMSE).

38. Investigations are required to identify the reasons why community nursing organisations receive relatively few referrals for clients with more advanced dementia.

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