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COMPLEX CARE: MEDICATION MANAGEMENT FOR PEOPLE LIVING IN THE COMMUNITY WITH DEMENTIA & CHRONIC ILLNESS

INTRODUCTION

A research project is about to commence in RDNS that will aim to develop, trial and evaluate a person-centred care framework for people living in the community with dementia and other chronic conditions who are at risk of medication misadventure. Medication management is a significant activity for RDNS with 40% of all RDNS clients receiving assistance with medications.

The project partners are: Quality Use of Medicines and Pharmacy Research Centre at the University of South Australia; the Royal District Nursing Service of SA Inc Research Unit, and the South Australian Divisions Incorporated (SADI) of General Practice. An Australian Government Initiative, this project has been funded by the Department of Health and Ageing and will commence in 2007. To inform this project, we have undertaken a comprehensive literature review, important aspects of which have been reported in this paper.

WHAT DID WE ASK AND WHAT DID WE DO?

The issues around medication management for this client group were explored and the questions that directed the review were;

How does cognitive impairment affect medication management?

What constitutes Quality Use of Medicines and how is it achieved in this client group?

Literature relating to the role of the primary health care team in both the international and Australian context was sought, with particular focus on chronic illness, dementia and medication management. The selected literature needed to be published in English, have relevance to the research questions and the Australian context, and published between 1996 and 2006. The search used Google, CINAHL, Medline and Cochrane. The search terms and phrases used were: dementia and medication management, dementia and medication administration, dementia and community care, dementia and care planning, home medicine reviews, medication management and community, community pharmacist and medication review, community nursing and medications and medication review. Professional websites were also accessed.

WHAT IS THE IMPACT OF DEMENTIA?

'*Dementia is a progressive and disabling condition, primarily of older persons, that can bring turmoil and anguish to those involved. The progression of dementia over many years is often categorised as mild (early stage), moderate (middle stage) and severe or advanced (late stage), before the person dies*' (Access Economics 2003:10). Dementia is a syndrome associated with a range of diseases that can be characterised by the progressive impairment of brain functions, including language, memory, perception, personality and cognitive skills. The cognitive, psychiatric and behavioural manifestations of dementia may include memory problems, communication difficulties, confusion, wandering, personality and behaviour changes, depression, delusions, apathy and withdrawal (Australian Institute of Health and Welfare (AIHW) 2004).

The incidence of dementia doubles every 5.1 years after the age of 65, and affects 24% of people aged 85 and over. The prevalence of dementia will grow rapidly over the coming decades due to the ageing population (Access Economics 2003). The AIHW report (2004) states that 96% of the Australian population aged 65 years or more who were reported as having dementia also required assistance with either self care, mobility or communication. Although dementia in people aged less than 65 years is less common, this group may have special needs due to issues such as employment and financial considerations if they are unable to work. Furthermore the disease is thought to progress faster in younger people (Howcroft 2004). In Australia around half of the people diagnosed with dementia live in the community and are assisted by home-based and community care programs which are funded by Commonwealth and State government (Access Economics 2003).

Many people with dementia also have other chronic illness. It is this combination of health conditions that adds to the complexity of health care provision. Chronic illness is often the reason that medication is being administered. It is recognised that people with chronic diseases use health services and medicines frequently and over extended periods of time (National Health Priority Action Council (NHPAC) 2006). It is widely accepted that taking medicine is a complex task that places both cognitive and

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An Australian Government Initiative

physical demands on older people (Beckman et al. 2005, Albert et al. 2003). Cognitive impairment has been associated with medication management mis-adventure (Ruscin & Semla 1996 cited in Beckman et al. 2005).

Diagnosis and assessment of dementia helps to distinguish dementia from the memory and cognitive impairment that occurs with ageing and from other disorders such as delirium, major depression or substance misuse. It is important to distinguish between the different types of dementia because they can have different features of onset, treatment and progression (Access Economics 2003). Alzheimer's Disease is the most common form affecting approximately 70% of people who have dementia (AIHW 2004). Other common types are vascular dementia, dementia with Lewy bodies, and fronto-temporal lobe dementia. Alzheimer's Australia advocates for early diagnosis so the person and the family may benefit from drug treatments, support and planning.

NATIONAL PRIORITIES, STRATEGIES AND CARE FRAMEWORKS

The National Chronic Disease Strategy provides an overarching framework for improving chronic disease prevention and care across Australia. There are varying levels of care required for people with chronic disease. Clients with chronic illness and dementia will frequently require care coordination. A core principle of the strategy is to achieve person centred care and optimise self-management. The aim of person centred care is that the individual is at the forefront and centre of their own health care. For this to occur, the health system needs to be driven by the outcomes which are relevant to the person, their family and carers.

The care of people with dementia who also have chronic illness requires coordinated, tailored, and flexible care processes. In Australia, Aged Care Assessment Teams (ACATs) are multidisciplinary teams that determine eligibility for admission into residential aged care and for Community Aged Care Packages (CACPs) or Extended Aged Care at Home (EACH) places. They may also recommend a range of Home and Community Care (HACC) services. The HACC Program provides community care services to frail aged and younger people with disabilities and their carers. The aim is to provide a comprehensive, coordinated and integrated range of basic maintenance and support services. The ACAT team will assess and identify the physical, medical, psychological and social needs of older people, their families and carers. The AIHW data from 2002 found that 20% of ACAT assessments were people who had dementia (AIHW 2004).

CACPs are individually planned and coordinated packages of community aged care services, designed to meet older people's daily care needs (Department of Health and Ageing 2004). CACPs are targeted at frail older people living in the community who require management of services because of their complex care needs arising from their physical, social and psychological status. Services may include personal care, sensory communication, domestic help and control and administration of medication. The EACH Dementia program provides coordinated and managed packages of care to frail older people with dementia who experience behaviours of concern (Commonwealth Department of Health and Ageing 2005). These people will usually have complex needs that require a level of case management. Key services and strategies are similar to other packages but have a focus on the needs of the client with dementia such as providing additional assistance with managing behavioural problems (Commonwealth Department of Health and Ageing 2005). In addition, Alzheimer's Australia manages many national programs that provide education, counselling, helplines and support to those living with dementia and their carers.

MEDICATION MANAGEMENT

The National Medicines Policy (2000) defines medicine as 'prescription and non-prescription medicine including complementary healthcare products'. It is estimated that more than 140,000 people in Australia are hospitalised every year for reasons that are medication related. Of these, approximately 50% of all medication incidences where the person required hospitalisation were considered preventable (Commonwealth Department of Health and Ageing 2002 cited in Roughhead et al. 2004). In addition to these figures, there are up to 400,000 adverse drug events that may be managed within general practice each year (Australian Council for Safety and Quality in Healthcare 2002 cited in Hodgkinson et al. 2006). The financial burden of these medication related incidents has been estimated at more than $350 million per year (Roughead et al 1998 cited in Hodgkinson et al. 2006).

Various factors may contribute to medication incidents in the community setting. Errors can occur during prescribing by the GP, dispensing by the pharmacist or misunderstanding by the consumer or carer. Polypharmacy, cognitive status, older age, living alone and cost of medication can all contribute to medication misadventure in the community setting (Ellenbecker et al. 2004). Other factors contributing to medication error include inadequate continuity of care and/or multiple healthcare providers.

People with dementia may be prescribed a high number of medications particularly if they have other chronic conditions. Since the introduction of acetylcholinesterase inhibitors the importance of medication for dementia has increased. These drugs work best in the mild and moderate stages of Alzheimer's Disease but evidence is growing that they may also be effective at other stages. Trials indicate that consistent prolonged use of the anti-dementia drugs delays the progression of symptoms of dementia in the majority of people for nine to twelve months (Access Economics 2003). A variety of medications are also used to treat the symptoms of dementia such as insomnia, restlessness, hallucinations, hostility and agitation. People with vascular dementia may be treated with aspirin and other blood thinning

agents to decrease the risk of stroke (Access Economics 2003). Many natural, traditional or alternative treatments are also used with dementia such as acetycholine support, antioxidants, herbal treatments to name a few.

THE ROLE OF THE REGISTERED NURSE IN THE QUALITY USE OF MEDICATIONS

Medicine, as a major component of therapeutic treatments, is most often administered by registered nurses. Community nurses work collaboratively with individuals, medical practitioners, pharmacists, and families and significant others to minimise negative reactions and optimise therapeutic outcomes for those treated with medicines. District nurses can provide long term home visits for medication management for clients who are confused, cannot self administer their medications, have no carer able to manage medication, or have no access to pharmacy dosette/Webster pack services. Fundamental to medication administration is assessment. It may take several visits by a nurse to determine cognitive status as the client may initially present as being cognitively coherent. The role of Community Registered Nurses in quality use of medicines relies upon:

Supporting and promoting an advocacy role including:

- Ensuring information is available so that individuals can make informed choices about their treatment with medicines
- Encouraging self administration of medicines where this can be safely undertaken
- Reconciling the individual's lifestyle and other needs with the management of medicines.

Meeting best practice standards for administering medicines and monitoring responses to medicines including:

- Implementing comprehensive assessment and monitoring to ensure that medicines are administered for best therapeutic effect
- Implementing appropriate measures if individuals experience adverse effects to medicines
- Contributing to regular reviews of prescribed and non-prescribed medicines
- Ensuring that medicines are stored in accordance with manufacturers' recommendations, that legislative requirements for safe keeping are met, and that administration processes are safe.

Ensuring the proficiency and professional competence of health professionals in quality use of medicines including:

- Providing ongoing education, which reflects specific nursing knowledge and experience.

Creating administrative frameworks that support the quality use of medicines including:

- Ensuring that only qualified nurses administer and monitor the use of medicines.
- Articulating policies and protocols to ensure the safe, effective delivery of medicine regimens (Royal College of Nursing, Australia 2004).

Registered nurses have a pivotal role in medication administration and are ethically and legally accountable for their practice in administering, delegating and monitoring medicine regimens.

HOW DOES COGNITIVE IMPAIRMENT AFFECT MEDICATION MANAGEMENT?

Dementia is a decline of reasoning, memory, and other mental abilities (the cognitive functions). People with dementia have limited cognitive resources by which to process information correctly, which puts them at high risk of medication misadventure. Dementia causes a disturbance in cognitive abilities and behaviours, which is often referred to as 'executive function' (Hayes *et al.*, 2006). Cognitive resources are also affected in the normal ageing process. The ability of people to process information decreases with age but automatic processing is not affected. This means that once a medication regimen is incorporated into people's lives, it can be automatically processed. However, any change in medication regimen will put more cognitive demand on the person (Brown & Park 2003 cited in Beckman *et al.*, 2005).

The importance of clients being involved in managing their own medication was revealed in the findings of a study by Husayn et al. (1990). Two hundred and sixty one patients attending a geriatric service were asked to recall the details of their usual medications by memory alone. Participants were inpatients, visiting as an out-patient and attending as day patients. Participants were asked details about their medications such as; the person responsible for administering medications, the name of the medication, the exact dosage of medication, the frequency of taking the drug and the reason for taking the drug. Of the 261 participants, 166 (64%) administered their own drugs, 30% were given drugs by a family member or friend and 6% were given medications by a health or social service professional. Results were that people who had administered their own drugs were able to give fuller drug histories. Patients had been more accurate with the 'mechanical' aspects of drug administration such as dosage and frequency of administration. Participants were not able to consistently recall the name of the drug or the reason for administration, indicating that many older people take medications without understanding the reason for it.

An Australian study by Griffiths et al (2004) used a pre-post test design to investigate the way in which older (n=113) people who were living at home and receiving community nursing care were able to manage their medications. The assessment of the ability for participants to manage their medications highlighted that only 8.3% were able to complete all tasks successfully, with the majority making one or two errors (54.2%). Failing eyesight was often an issue with 37.5% of participants not being able to differentiate between blue, green and lavender. This is important if nurses provide instructions about medications based on colour.

NATIONAL STRATEGIES FOR QUALITY USE OF MEDICINES

Quality Use of Medicine (QUM) was one of the major objectives of the National Medicines Policy developed by the Department of Health and Ageing (2000). QUM means selecting management options wisely, choosing suitable medicines and using medicines safely and effectively (Australian Pharmaceutical Advisory Council 2005). In addition, The National Strategy for QUM and the Strategic Action Plan are intended to assist the QUM partners to become more aware of the QUM policy framework and approach and enable them to integrate their own activities with the National Strategy (Commonwealth of Australia 2002). The goal of the National Strategy is to make the best possible use of medicines to improve health outcomes for all Australians.

The National Medicines policy aims to 'meet medication and related service needs, so that both optimal health outcomes and economic objectives are achieved' (Department of Health and Ageing 2000). The four central objectives are;

- Timely access to medicines at a cost individuals and the community can afford
- Medicines meeting appropriate standards of quality, safety and efficacy
- Quality use of medicines
- Maintaining a responsible and viable medicines industry

The Australian Pharmaceutical Advisory Council (APAC) has developed a number of guidelines to assist health professionals to achieve QUM (Australian Pharmaceutical Advisory Council 2005, Australian Pharmaceutical Advisory Council 2002, Australian Pharmaceutical Advisory Council 2006). The administration of medicines by health workers in the community can be guided by the APAC community document (Australian Pharmaceutical Advisory Council 2006) which states 'health care professionals, care workers and service providers all play an important role in making sure that consumers who live at home receive suitable information and/or assistance so that they take their medicines correctly'. The principles acknowledge the importance of communication and coordination between health professionals, carers, care workers and service providers to ensure safe and effective administration of medicines.

LIMITATIONS OF CURRENT SERVICE DELIVERY

There exists a number of limitations to the current systems of care:

Crisis approach to care

Surveys have shown that only about half of GPs were able to recognise mild dementia and about 70% were able to identify moderate dementia (Creasey & Brodaty 1998 cited in Access Economics 2003). The Access Economics report (2003) highlighted that GPs may not be up to date with information about dementia, understanding the family and carers role or how to access support services. A small qualitative study revealed that carers had considerable difficulty finding out about and gaining access to community care even when they had a long term GP (Bruce and Paterson 2000, Bruce et al. 2002).

Problems with access to community services

Many GPs are still uninformed about advances in dementia assessment and diagnosis, have difficulty in assessing dementia and do not refer the person with dementia on to community services (Access Economics 2003). In a qualitative Australian study carers reported confusion about whether the diagnosis of dementia had actually been established. This meant that three carers did not seek help because they were unsure whether or not their relative qualified for support (Bruce and Paterson 2000). This was also identified by Dewar et al (2002) who found that carers in their focus group also needed a diagnosis in order to legitimise their need for support services. Carers felt that the dominant medical model of care which classifies individuals according to pathology can limit carers access to professional care. These studies can only be used as a guide because they used small convenience samples.

Miscommunication about medications has been reported as an issue for community nurses (Koch & Visentin 2003). For example, medication authorisations may not match the medications the client has in the home or there may be a discrepancy in the dose or frequency prescribed. Ellenbecker et al (2004) cites the example in which the physician may instruct the client to change their medication without notifying the nurse who is to administer it, leading to confusion and errors.

Psychosocial needs not being recognised by health care workers

Bruce and Paterson (2000) found that the level of burden carers and people with dementia were experiencing was not fully understood or appreciated by health care workers. Zarit et al 1999 (cited in Bruce and Paterson 2000) also found that community support services often fail to reach those who need it most. Dewar et al (2002) found that carers did not emphasise their own health needs when visiting the GP as they found it difficult to express their own feelings to health professionals.

Evaluation has not included the person with dementia

Biernacki (2000) is concerned that the evaluation of dementia services has and is hindered by the difficulties of involving those with dementia. She argues that there is little or no evidence on how to reflect the views and experiences of people with dementia when planning or assessing services. The current practice of substituting carer or family opinions for those of the person with dementia may not be best practice. What is appropriate for carers or family may not be appropriate for the person who has dementia. There may be family dynamics that impact on the views offered by the caregiver (Biernacki 2000). Whilst Biernacki (2000) recognises the difficulty in getting opinions from people with dementia particularly when considering how their cognitive status impacts on decision making ability she argues that the challenge must be taken up.

Consumers had difficulty being active partners in medicine management

The Pharmaceutical Health and Rational use of Medicines (PHARM) Consumer Sub-Committee (2001) conducted research with representatives from over 110 consumer groups across Australia. Consumers reported a number of factors that made it difficult for them to be active partners in the use of their medicines. These factors were; difficulty in accessing important information when it is needed, inadequate communication between consumers and pharmacists and difficulty managing regimes of multiple medicines as well as accessing help to overcome that difficulty. Consumers proposed there was lack of coordination between different prescribers, hospitals and GPs. Carers reported having problems accessing information about their family members medicines due to privacy concerns. Consumer groups reported language barriers between non-English speaking consumers and their doctors and pharmacists. There was also difficulty in obtaining information about prescription medicines in languages other than English. Interpreters were not being used when needed which meant that information about medicines was at a superficial level. Consumers also claimed that doctors were not attuned to cultural differences related to medicines.

HOME MEDICINE REVIEW

The Australian HMR has been externally evaluated. Issues identified included difficulties in incorporating HMRs into traditional general practice business models, pressures on general practice, perceptions by GPs that the HMR process is complicated and time-consuming, insufficient numbers of accredited pharmacists, reluctance by GPs to work with pharmacists in the way HMR requires, dissatisfaction with some aspects of pharmacy HMR services received, lack of client pressure. There were some issues noted relating to variable levels of contact between GPs and the pharmacist after the HMR report had been delivered. Further research is advocated to explore the way that GPs use the pharmacists HMR report and the extent to which they act on the suggestions and recommendations that they contain (Urbis Keys Young 2005). It should also be noted that the evaluation did not examine the nurses' role in medication review and that within the HMR model the nursing role has not been clearly defined.

There are groups in the community that have been under-serviced by the HMR such as people from culturally and linguistically diverse backgrounds (CALD), Indigenous communities and people living in isolated or sparsely populated areas. A study carried out by Bajramovic Fejzic and Tett (2004) explored the use of home medicine review for people from the former Yugoslavia who had become Australian residents. It has been reported that clients from CALD backgrounds have twice the error rate of an English-speaking group in medication use (Shaw et al 1977 cited in Bajramovic Fejzic and Tett 2004).

What is the role of the community nurse in the HMR process?

The role of the nurse in the medication review process has not been clearly articulated within the Home Medicine Review documents. Community nurses have a responsibility to evaluate the clients ability for medication self management (Cox Curry et al. 2005, Ellenbecker et al. 2004). Griffiths et al (2004) states that while the HMR has assisted to formalise links between GPs and pharmacists there has been less progress in developing formal collaborations involving community nurses. The administration of medications and the monitoring of their effects is an important nursing function yet there has been little research that explores the potential effectiveness of community nurses in medication management. A literature review by Griffiths et al (2004) found little evidence to support nurse-led interventions. Another literature review by Baker et al 1994 (cited in Griffiths et al. 2004) concluded that nurses contribute in two ways to identify problems with medication regimes and to promote adherence. Firstly it is important for nurses to develop collaborations with other health professionals that provide opportunities for sharing client information. Secondly nurses can monitor medications and provide education and other medication-related information to clients and/or carers. Johnson et al (2002) cited in Griffiths et al (2004) claim that the clients ongoing contact with community nurses provides an ideal opportunity for assessment, evaluation, intervention and liaison with GPs and pharmacists to prevent medication problems. Community nurses have reported difficulties in communicating with the client's doctor and that they were out of the information loop (Visentin and Koch 2003).

Another community nursing project aimed to develop and test a systems based approach for community nurse referral for a HMR and to identify any barriers to their uptake (Kyle and Nissen 2006). There was a potential client database of 2700 from three different district nursing services but only 5 HMR requests were sent to GPs over the seven months of the study. Only two of these resulted in a completed HMR and this was clearly a disappointing result. The authors suggest that this may in part be due to lack of awareness about the HMR by consumers thus making it more difficult for nurses to get consent.

How effective are home medicine reviews?

A significant number of medication problems are identified during home medication reviews. For example a study conducted in Australia examined the nature and type of medication-related problems that occurred in a large sample of people (n=1000) who were living in the community and who were deemed to be at risk of medication misadventure. The findings were that 90% of the clients experienced at least one medication related problem (Roughhead et al. 2004).

Sorensen et al (2005) found an association between medication related risk factors and poor patient health outcomes. Key medication related risk factors included; lack of any medication administration routine, therapeutic duplication, hoarding, confusion between generic and trade names, multiple prescribers, discontinued medication repeats retained, multiple storage locations. The findings supported the theory that poly-pharmacy and medication related risk factors

as a result of poly-pharmacy are correlated to poor health outcomes (Sorensen et al. 2005). It was found that the number of medications found in the home was a better indicator of medication-related risk factors than the number of medications that the client reported to be taking. This highlights the importance of home visits as opposed to simply asking clients to bring medications to an appointment.

Stewart et al (1998) researched with clients who were deemed to be at high risk for rehospitalisation were visited at home by the study nurse and pharmacist. Clients who showed poor medication compliance at the home visit received more intensive intervention (n=314). Usual care consisted of a follow up visit with their GP two weeks post discharge. It was found that home based intervention led to fewer deaths and hospital readmissions than usual care. Using this initial cohort the researchers then compared all cause mortality and recurrent hospitalisation during a 7.5 year follow-up (Pearson et al. 2006). They found that even during the prolonged follow up the home based intervention was associated with significantly fewer short to long term admissions. Clients with dementia and chronic illness could be targeted in a similar way. This intervention also included home visits by a nurse and this was not seen in other studies.

A randomised controlled study carried out in three Australian states by Sorensen et al (2004) examined the effectiveness of a multidisciplinary service model delivering medication review to patients at risk of medication misadventure in the community. The multidisciplinary service model consisted of GP education, home visits, pharmacist medication reviews, primary healthcare team conferences, GP implementation of action plans in consultation with patients, and follow-up GP visits for monitoring. The authors reported that 92% GPs who were involved with the intervention and 94% of the pharmacists believed that the model had improved the care of participating clients.

CONCLUSION

The community care of clients with dementia is often complicated because many have age related disability and also have chronic illness. The goal of team based care in which the person's needs are the central focus features strongly within the literature. Community nurses aim to care for people as individuals and use care approaches that enable them to make choices about their own care. This is achieved through ongoing comprehensive assessment and integrated provision of services. The term 'person-centred care' is mainly used in the literature about older people, particularly in relation to dementia care. Although the meaning of the term varies, 'person-centred' or 'quality' care is: user focused; promotes independence and autonomy rather than control and importantly involves people having access to reliable and flexible services to assist with medication administration.

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