THE INTERACTION BETWEEN HOSPITAL AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CARERS

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ABBREVIATIONS

ACAT  Aged Care Assessment Team
ADI   Alzheimer’s Disease International
AIHW  Australian Institute of Health and Welfare
AlzNSW Alzheimer’s Australia NSW
CACP  Community Aged Care Package
Com Packs Community Packages
DBMAS Dementia Behaviour Management Advisory Services
EACH Extended Aged Care at Home
ED    Emergency Department
HACC  Home and Community Care
HDS   Hospital Dementia Services (Project)
LOS   Length of stay
MDT   Multi-Disciplinary Team
NSW   New South Wales
PWD   Person with dementia
TACP  Transitional Aged Care Program
CONTENTS

Abbreviations 4
Executive Summary 6
Recommendations 10
1. Background 8
2. Literature review 11
  2.1 The extent of the growing challenge of dementia and the policy response 11
  2.2 Social support for people with dementia and their carers 13
  2.3 Hospital-based experience that influence community-based service needs post-hospitalisation 14
  2.4 Community-based services post-hospitalisation 14
3. Methodology 16
  3.1 The Research Team 16
  3.2 Recruitment 17
  3.3 Data Collection 17
  3.4 Analysis
    Table 3.2 Focus groups for Carers 18
    Table 3.3 Telephone interviews with carers 18
    Table 3.4 Validation Group 19
  3.5 Ethics
    Table 3.5 Focus Groups 19
4. Findings 22
  4.1 Carers’ perspectives on the transition from hospital to home for people with dementia 25
    Table 4.1 Carer themes 25
  4.2 Community-based service providers’ perspectives on the transition from hospital to home
    for people with dementia 27
    Table 4.2 Community-based service providers 29
  4.3 NSW Hospital Dementia Services project site visit data related to discharge and
    community-based services 30
    Table 4.3 Key issues arising from HDS data 31
  4.4 Community-based services 2011 (HDS) to 2013 (current study) 32
5. Discussion 34
  5.1 Dementia 34
  5.2 Hospital paradox for people with dementia and their carers 34
  5.3 Complexities of community-based services for people with dementia 36
  5.4 Patterns of service use by people with dementia and their carers 37
6. Conclusion and recommendations 38
  6.1 Options involving cash payments
  6.2 Good practice in respite
  6.3 Furthering good practice in respite
References 40
Attachments
  1 Information sheet 43
  2 Consent form 44
  3 Complaints form 45
  4 Questions for carer focus groups and telephone interviews 46
  5 Questions for community-based service providers 47
EXECUTIVE SUMMARY

Currently there are 109,000 people with dementia in NSW (AIHW, 2012a) and without a major medical breakthrough those numbers are expected to reach 132,000 by 2020. Alongside this increasing rate of dementia prevalence is the high number of people with dementia admitted to hospitals in NSW.

The average cost of hospital care for people with dementia is generally higher than for people without dementia. According to the recent Australian Institute of Health and Welfare (AIHW) publication Dementia care in hospitals: costs and strategies, the total cost of care in NSW public hospitals for people with dementia was estimated to be $462.9 million, of which around 35% may be associated to dementia (AIHW, 2013).

More than half the number of people living in residential care have a diagnosis of dementia and the costs associated with this care impact significantly on the health sector. By the 2060s it is projected that 11% of the health and residential aged care sector spending will be on dementia care (Access Economics, 2009b).

National health, hospital and aged care reforms and state based community care policy and programs encourage older people to stay living in their homes for as long as possible rather than transferring to residential care. In order to support this policy agenda, and with 70% of people with dementia living in the community (AIHW, 2012a) further information about the specific challenges for people with dementia is required. Hospitalisation and the subsequent return to home for people with dementia is one such challenge.

This research sought to investigate and understand the perceptions of carers of people with dementia, and community-based service providers, who had experienced, in some capacity, the transition from hospital to home.

The findings suggest that the hospital experience and subsequent discharge has a significant impact on the experience of transition from hospital to home for a person with dementia and their carer. Carers met their responsibilities with a high degree of stoicism but many expressed the impact of physical and emotional stress. During the hospital stay carers reported being required to assist with daily care of the person with dementia but yet, were often ignored regarding their knowledge of the person, in deference to the often unpredictable capacity of the person with dementia to provide accurate information. Carers found access to services was often limited and inappropriate to their needs and they valued informal networks, such as other carers, as a source of information about service availability.

Many community-based service providers agreed that services to assist the person with dementia and their carer during the transition from hospital to home were complex and difficult to navigate, due to lack of coordination. Service providers spoke of the need for a dementia-specific case worker to guide carers through the process of selecting and evaluating services during the transition time and beyond.

Carers told us that the transition from hospital to home should be: easily navigated; reduce the risk of re-admission; and ensure both the person with dementia and their carer are given maximum opportunity to have their needs met. Therefore, people with dementia require specific care and support to facilitate good outcomes regarding their care, modes of communication and treatment.

There is an evident need to increase dementia specific training for hospital staff that incorporates knowledge about the nature of dementia, the consequent care required and availability of specific community services. This will ensure appropriate and timely
discharge planning begins at the point of admission and continue throughout the hospital stay.

A better, person-centred, transition process from hospital to home is urgently required. Better coordination and consultation between hospital staff, carers and community-based service providers is essential to support carers as they navigate the complex and copious number of service options available to them.

As a result of the work carried out in this project, with carers and community-based service providers, critical insights from the research participants have drawn recommendations for further consideration:

1. Increase provision of dementia-specific education and training for hospital staff.
2. Develop and incorporate valuable informal networks and exchanges, which can exist between hospitals and community-based services, into discharge planning and referral pathways to overcome system demarcation issues.
3. Increase and improve access to post-hospital and rehabilitation services designed for people with dementia and their carers.
4. Begin active discharge planning by multidisciplinary teams for people with dementia on admission to hospital.
5. Continue investment in consumer led case management services to enable timely service access for people with dementia who leave hospital, thereby reducing re-admission rates.
6. Develop innovative systems to support people with dementia and their carers during the hospital stay such as a symbol to represent a patient with cognitive impairment and the Top5 carer’s tool.
7. Expand systems to support people with dementia in the transition across health and community sectors such as the Key Worker Program.
1. BACKGROUND

The ageing population of Australia continues to grow, and alongside it, the number of people with dementia. Currently there are 321,600 people living with dementia in Australia. Without a cure this number is expected to rise to almost 900,000 by 2050 (AIHW, 2012a).

Dementia is the single greatest cause of disability in older Australians (Access Economics, 2009) and the third leading cause of disability burden overall (AIHW, 2012a). Most people with dementia inevitably require some form of care which is generally provided by informal (family) carers. These carers are very likely to experience strain, with significant psychological and physical consequences, including a higher mortality rate (Alzheimer’s Disease International (ADI), 2009). The social and economic impact of dementia on the community is high.

Federal aged care reforms and state based community care developments encourage older people to stay living in their homes for as long as possible rather than transferring to residential care. Consumer directed care will underpin all future service delivery and, in the wake of dementia becoming a National Health Priority in 2012, increased coordination and collaboration across government and non-government agencies is being promoted as the ideal.

In order to support this policy agenda, and with 70% of people with dementia already living in the community (AIHW, 2012a), further information about the specific challenges for people with dementia and their carers is required. Hospitalisation and the subsequent return to home for people with dementia is one such challenge.

Severe cognitive impairment, poor nutrition, dependency for activities of daily living and carer stress are predictors for hospitalisation for people with dementia. The reasons
for admission vary and are often related to co-morbidities rather than the symptoms of dementia. The numbers of people with dementia admitted to hospital are rising due to the increasing need for acute care for this cohort. However the dementia specific skills of hospital staff are often limited and hinder the identification and management of the symptoms of dementia. This increases the risk of falls, the potential use of inappropriate chemical and physical restraint, and prolonged hospitalisation often resulting in secondary effects of hospitalisation such as loss of muscle tone and strength (D’Amburoso & Cadogan, 2012).

The NSW Hospital Dementia Service (HDS) project was undertaken by the AIHW, the University of NSW and the University of Canberra to investigate how hospital-based aged care and dementia services influence outcomes for people with dementia admitted to hospital in NSW in 2006-07 (AIHW, 2013). The findings from the HDS project tell us:

• People with dementia, in general, do not have a good hospital experience
• People with dementia have longer hospital stays and higher rates of readmission to hospital
• The admission process can be traumatic and confusing, often via the Emergency Department
• Hospital design is not conducive to the wellbeing of people with dementia and their carers
• Almost half (47%) of patients with dementia did not have dementia recorded as a diagnosis
• People with dementia generally stay in hospital longer and have higher associated costs of care and
• A range of strategies were identified that could improve outcomes for people with dementia and reduce the costs of care.

The interaction between hospital and community service providers was reported in the HDS project as a significant finding and was strongly associated with length of stay in hospital and subsequent readmission.

Given the potential hazards of hospitalisation for older people with dementia, it is important that unnecessary extended hospitalisations are prevented and potential service gaps are addressed (AIHW, 2013, p.1)

The HDS project also noted the difficulties that can arise when discharging people with dementia from hospital into mainstream services in the community. It cited Spanio & Michaels (2007) work on interagency care coordination protocols for transitions of care which noted that service coordination is essential for effective discharge practice. Due to the unique complexities of dementia, effective discharge practice would begin at admission, include carer’s advice about the person with dementia and provide the carer with a discharge plan and links to post-discharge services (AIHW, 2013).

While the HDS project clarifies the key elements in dementia-specific care for people with dementia in hospital, it did not seek out carers’ views of their experiences. Consequently, this project undertaken by University of Canberra, Alzheimer’s Australia NSW (AlzNSW), and University of NSW and funded by NSW Ageing, Disability and Home Care, builds on the previous work undertaken in the HDS project to obtain qualitative data on the experiences of consumers regarding the interaction between hospital and community-based services, including services such as Home and Community Care (HACC) and disability services, for people with dementia and their carers.
This project is consistent with the principles underpinning the NSW Dementia Services Framework (NSW Health, 2010). The project recognises the importance of social inclusion for people with dementia and their right to remain living at home for as long as possible. It identifies good service planning and coordination, which includes the voice of the consumer, as key enablers to quality dementia care.

**AIM**

The aim of the project is to investigate the experiences of people with dementia and their carers when the person with dementia is hospitalised and discharged into the community.

**PURPOSE**

The purpose of this report is to outline the findings from the research project and increase our understanding of:

- The experiences of the person with dementia and their carer regarding the hospitalisation of the person with dementia
- The experience of discharge from hospital for the person with dementia and their carer
- The use of community services before and after discharge into the community, by the person with dementia and their carer
- The met and unmet needs of the person with dementia and their carer during the hospital stay, discharge and return to home.

The following chapters provide a literature review of current work published in Australia and internationally, an outline of the methodologies used for this study, the findings of the investigation and discussion and analysis. Conclusions are drawn and recommendations provided to meet the community service needs of people with dementia and their carers returning home following a hospital stay, to improve quality of life and reduce the incidence of hospital readmission.
2. LITERATURE REVIEW

As Australia entered the 21st century, the burden of an ageing population and a rise in chronic illness on health services became increasingly evident. While Australia has a sophisticated health care system, continuing to meet the challenges of chronic illness through tertiary (hospital-based) services is expensive. The policy response to the rising burden of chronic illness was to invest in primary health care, including further development of community-based services. While there is emerging research into the support service requirements for spouses, children and close friends of people living with dementia at home, the specific needs of people with dementia and their families when discharged from hospital to home require further investigation.

2.1 The extent of the growing challenge of dementia and the policy response

Globally, the number of people affected by dementia is anticipated to rise exponentially as populations’ age, representing one of the greatest challenges to health and social services. In 2010, it was estimated that, worldwide, 35.6 million people have dementia and that this number will double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (ADI, 2009). An AIHW report released in September 2012 noted that at least 298,000 people are living with dementia in Australia and by 2020 the number is estimated to be 400,000. Therefore in a period of less than ten years the number of people living with dementia will have risen by a third, by 2050 the numbers are estimated to triple from the current figure to over 900,000 (AIHW, 2012a; Access Economics, 2009b). In a study by Deloitte Access Economics (2011), NSW was projected to have the greatest number of people with dementia now and in the future, with 91,038 cases in 2011 and 303,673 expected in 2050.
Dementia is not a singular disease, rather the term dementia covers a range of diseases that are characterized by being a usually progressive group of symptoms that include cognitive impairments, psychiatric and behavioural symptoms, and reduced ability to perform activities of daily life (ADI, 2009). By definition, the deficits associated with dementia cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning (American Psychiatric Association, 2000). Most types of dementia are characterised by loss of memory and impairment in other cognitive abilities. Alzheimer’s dementia is the most common type of dementia accounting for 50-75% of all cases worldwide (AIHW, 2012a). Whilst there are people with younger onset dementia, the majority are over 65 years.

Like other older Australians, people with dementia are at risk of developing chronic illnesses such as diabetes and heart disease, and at higher risk of injury from falls. People with dementia have higher hospitalisation rates than those without dementia and when they are admitted for more than an overnight stay, people with people with dementia stay twice as long as those without dementia (18.3 days vs 9.1 days) (AIHW 2012b).

Dementia is the leading cause of dependency (need for care) and disability for people older than 60 years (ADI, 2009). For people aged 65 years and over, dementia was the second leading cause of overall burden of disease and the leading cause of disability burden, accounting for a sixth of the total disability burden in older Australians (AIHW, 2012a). At some stage in the disease process, most people will require some form of care, generally provided by informal (family) carers. These carers are very likely to experience strain, with significant psychological and physical consequences, including a higher mortality rate (ADI, 2009). The impact in the community is costly, both economically and emotionally.

People living with dementia may have multiple carers, from close family members to professional carers through to wider community networks. However, primary carers are “persons, who spend most of the time with the person with dementia”, and secondary caregivers, are those family and friends who “play a supplementary role to the care of a relative” (Gaugler et al, 2009). In Australia, 42% of primary carers of persons with dementia were the spouse/partner and 44% were the son or daughter (AIHW, 2012a). When only co-resident primary carers are reviewed, 57% were the spouse/partner and 36% were the son or daughter (AIHW, 2012a). Carers can also be friends, volunteers and other community members. If the spouse is the primary carer, it is more than likely that he/she will be between 65 and 84 years of age (AIHW, 2012a), and may also have multiple illnesses. There are geographic differences as well; Hansen et al (2005) noted that rural families are more likely than urban families to maintain a person with dementia within the family home.

In a study of 33,000 cases of Australians living at home, who had not previously used aged care services and had an aged care assessment in 2003-4, Karmel et al (2012) found that timely access to community care could be important in reducing rate of entry to residential care after hospitalisation. Further, this research group found that people with dementia are much more likely to be recommended for residential care than people with heart disease. With the incidence of dementia rising, this finding has profound implications for post-hospital community service provision.

2.2 Social support for people with dementia and their carers

The value of social support, and particular social networks, is critical in helping people remain at home. Carers are the key element in the social networks of people with dementia. The primary carer often first notices something is wrong, and shares the challenging journey of diagnosis and therapies and advocates for their spouse/partner or
parent (Galvin, Trodes & Richardson, 2005). As the person with dementia becomes more affected by the disease, the importance of primary carers in maintaining a social network, to reduce loneliness, increases (Moyle et al., 2011).

Similar to international trends, loneliness that may arise from a lack of social support exists among Australian people with dementia and their carers. Both people with dementia and their carers experience loneliness and organised activities such as bowls, shopping outings, religious and church related activities, as well as activities with formal secondary carers, were frequently described by both carers and people with dementia as being beneficial in reducing the experience of loneliness (Moyle et al., 2011). Carers respond well to supportive non-medical, non-pharmacological interventions aimed at psychosocial support. There have been several systematic reviews of psychological interventions for primary carers of people with dementia (Brodaty, Green & Koshera, 2003; Chien et al., 2011; Cooke et al., 2001; Cooper et al., 2007).

Despite evidence to suggest the value of social network arrangements to reduce the burden for carers, they may not connect the person with dementia with formal social and health support, which may constitute a disadvantage for both them and the person with dementia (Nelson et al., 2002). Reasons why carers do not use formal services include: the stigma associated to the diagnosis of dementia; perceived lack of need; care recipient’s refusal to accept help from services; service characteristics; and lack of knowledge about service availability (Brodaty et al., 2005). It would appear one of the challenges for service provision in the community for people with dementia and their carers is the diversity of people’s needs for social rather than clinical support and the requirement to balance the tension between high level policy solutions and local community (users) views.

2.3 Hospital-based experience that influence community-based service needs post-hospitalisation

Dementia is infrequently the principal reason for hospital admission in this cohort (Draper et al., 2011). The literature suggests there is a range of hospital-based experiences that influence post-hospitalisation community service needs. These experiences include on admission, existing dementia being recognised and diagnosed, adverse events in hospital that precipitate cognitive and functional decline as well as increased mortality, and the complexities related to co morbidities resulting in prolonged hospitalisation.

For frail, older people with dementia, hospital can be a dangerous and unfriendly place (Kurle, 2006). Hazards include poly-pharmacy, under-nutrition, skin tears, pressure areas, fall-related injuries, nosocomial infections and de-conditioning (Creditor, 1993). Co-morbid conditions often require multiple bed moves around the hospital and these can cause distress and exacerbate confusion, agitation and behaviour problems (Cunningham & Archibald, 2006; Doherty & Collier, 2009). Large and unfamiliar hospital environments are associated with patient disorientation and anxiety (Cunningham, 2006). People with dementia are also at increased risk of developing delirium in hospital (Draper et al., 2011; Watkin et al., 2011; Zuliani et al., 2011). Co-morbid dementia and delirium is associated with worse outcomes including increased risk of adverse events, mortality and length of stay (Lang et al., 2010; Watkin et al., 2011). These various adverse events are frequently reflected in episodes of agitated behaviour.

Cognitive decline after anaesthesia is attracting increased research attention. There have long been anecdotal reports that symptoms of dementia might commence after surgery. In some cases it is likely to represent the uncovering of an insidious process that has gone undetected before surgery. In others, post-operative delirium does not fully resolve. The extent to which the general anaesthetic might be responsible for the change is unclear but
there is enough concern for an anaesthetics consensus statement to conclude that there is sufficient evidence to warrant further investigation with more definitive research (Baranov et al., 2009).

The impact of delirium and other adverse events of hospitalisation are mirrored in length of stay (LOS), mortality and post-discharge outcomes for people with dementia (Sampson et al., 2009; Guijarro et al., 2010; Draper et al., 2011; Sampson et al., 2013). The relatively higher complexity of patients with dementia contributes to longer hospital stay and this has an impact on patient’s physical and mental state on discharge (King et al., 2006). The average length of stay for people who had a co-morbid diagnosis of dementia was 18 days, six times higher than the average length of stay for hospital separations for people without dementia (3 days) (AIHW, 2012a).

Reduced muscle tone, pressure sores and immobility are associated with functional decline and longer LOS (Lang et al., 2010; Zuliani et al., 2011). Functional status has been found to be the strongest predictor of discharge stability (Heppenstall, Hanger, & Wilkinson, 2009; Zekry et al., 2009). When a diagnosis of dementia was added, almost all patients were transferred to a residential aged care facility (Zekry et al., 2009).

The lack of knowledge of dementia for nurses and other hospital staff members is well established in the literature (Jones et al., 2006; Poole & Mott, 2003; Moyle et al., 2010; Borbasi et al., 2006). Hospital staff demonstrated limited understanding of the disease, with studies of nurses who report feeling frustrated and remorseful about the low quality of care delivered to people with dementia (Byers & France, 2008; Doherty & Collier, 2009). Lack of recognition that the patient has dementia may increase the risk of adverse events occurring, one study reported that staff members were only aware of the diagnosis of dementia in one third of patients that had an adverse event and that this lack of awareness may have contributed to the adverse event due to staff leaving instructions with the patient that they might not have been able to comprehend (Watkin et al., 2011). In managing the behaviours of dementia, restraint (chemical, physical, and close supervision) is employed to prevent harm to the individual (Jones et al., 2006; Moyle et al., 2010). Moyle et al (2010) label this care as ‘paradoxical care’ where patient safety is emphasized at the expense of dignity and well-being.

In an ethnographic study of people with dementia in hospital, Cowdell (2010) found that people with dementia reported the delivery of care and the experience of being in hospital to be distressing, as they did not know what was happening and they were often ignored. The study specifically noted that staff worked in habitual ways and showed a lack of empathy. The emerging evidence suggests that while hospital-based nurses are knowledgeable in the specialty areas such as cardiac disease, surgery or other specialized fields, they do not understand dementia.

Hancock et al (2003) in an Australian jurisdiction surveyed older patients/caregivers and nurses, with a focus on discharge planning. They found that nurses highly valued discharge planning but all respondents (patients/carers and nurses) were only moderately satisfied with this process (Hancock et al., 2003). Hospital staff knowledge of dementia, and strategies to manage the behaviours of dementia without restraint, may result in poor quality of care, and nurses’ lack of knowledge can also negatively impact on discharge.

2.4 Community-based services post-hospitalisation

The value of community-based services for people with dementia is emerging as a key factor in helping people with dementia stay at home. In a national study of hospital stays, researchers found that outreach and community-based specialist dementia
services reduced the use of hospitals by people with dementia, leading to improved patient outcomes, although post-hospital accommodation outcomes proved sensitive to the availability of high care community packages (Hales et al., 2006). In this section, the availability of services, including respite care and issues in the rural setting are reviewed.

In the Access Economics report (2009a), Making Choices, researchers found that home support services such as shopping, transport and cleaning were valued the highest by respondents (Access Economics, 2009a). Further packages that included respite services, either daily or for extended periods, were in 48% more demand than packages that did not include this option (Access Economics, 2009a). Finally, researchers found that a community centre that offers counselling, recreational activities, education and information services during the working week and on weekends would have 31% higher demand than when a community centre was not available (Access Economics, 2009a).

The care needs of people with dementia can be quite different than their pre-hospital needs, with transfer to a residential aged care facility from hospital more likely due to lack of available high care community packages (Hales et al., 2006). In Australia, the General Practitioner (GP) is the most common conduit to formal service provision. However, Parker, Mills and Abbey (2008) note that carers, if they themselves are in good health, may make decisions on when to access care. Parker et al (2008) conclude that a sense of duty of “caring for one’s own” reflected the stoicism of an older generation. In many ways, the carers of people with dementia are coordinating service usage and their interests need to be included in case coordination programs.

Once home from a hospital admission, the carer must work much longer hours to support the person with dementia to readjust to living at home and can be confronted by someone who is much weaker and displaying new or unresolved behaviours. Despite the receipt of transition or dementia community care packages, carer health can suffer when the person with dementia returns home from hospital. Carer health is a critical factor in the decision to transfer a person with dementia into a residential aged care facility (Runge, Gilham & Peut, 2009).

For people living in rural and remote areas, the lack of respite services (Innes et al., 2005) dictates that the local hospital can sometimes be used for respite care, with negative outcomes for the person with dementia and their carer. In a study commissioned by Alzheimer’s Australia WA (2007), service providers noted that a lack of services and provision of safety features in the home increased the likelihood of carer “burn-out” and hospitalisation and early admission of the client to residential care (Alzheimer’s Australia WA 2007). While hospitalisation should provide the carer with respite from the demands of caring, this study found that carers felt they had to be present at all times to supervise the person and to assist the person with eating (Alzheimer’s Australia WA 2007), offering little respite.

In terms of respite service use, Neville and Byrne (2002) report that there is no difference between urban and rural uptake of respite services. In the Scottish study of people with dementia in rural communities, some of the key reasons people report not taking advantage of formal services, such as respite, included the stigma associated with dementia in a small community (Mason et al., 2005; Hansen et al., 2005), lack of available services in local area (Innes et al., 2005), and the energy required to get ready for day care is not worth the effort (Innes et al., 2005). It would seem that respite services, while valued, may be difficult to access for a range of personal and situational reasons.

In conclusion, it is timely to investigate the community-based service needs of people with dementia and their carers after a hospital experience, to enable them to remain at home for as long as possible.
3. METHODOLOGY

The methodology for this research project was developed using a grounded theory approach. Grounded theory (Glaser and Strauss, 1967) is a method of qualitative research that enables researchers to build theory “from the ground up” (Corbin & Strauss, 2008). It differs from other qualitative approaches in that its focus is on discovering concepts that explain actions and interaction.

As a consequence, the research was designed to facilitate a comprehensive investigation of the experiences of carers of people with dementia during and following the hospitalisation of the person they care for as well as the views of community-based service providers. The use of grounded theory reveals the relationship between concepts and themes and delivers useful insight to inform clinical practice.

The research included a literature review to inform the project and identify gaps in this area of investigation, qualitative data from focus groups with carers and service providers and in-depth telephone interviews with carers. A comparative analysis between this research and that conducted in the HDS project was also undertaken.

3.1 The Research Team

A consortium approach was used to conduct the research project. The team comprised of researchers from AlzNSW, University of Canberra, University of NSW and AIHW. This brought together specialist knowledge in dementia and related services as well as research methods and practice.
3.2 Recruitment

Recruitment for carer and service provider participants was conducted state-wide across NSW and included Social Media posts on Facebook; flyer distribution across NSW including dementia service provider networks; dementia advisory services and AlzNSW consumer advisory groups and also carer support groups for carers. All participants were self-selected.

Carers made contact with AlzNSW by phone or email and their suitability was assessed. Criteria for selection of carer participants stipulated the participant must be the carer of a person diagnosed with dementia; the person with dementia must have been hospitalised in the last two years in NSW including any time spent in an Emergency Department; the person with dementia must have returned home and not placed in permanent residential care. This last criterion made recruitment difficult due to the high number of people with dementia who transfer from hospital to residential aged care rather than home.

For the in-depth telephone interviews a Consent form (Attachment 1), Information sheet (Attachment 2) and Complaints form (Attachment 3) were sent to the carer. Once the consent form was received by AlzNSW, with the participants’ permission, their contact details were assigned to one of three interviewees and a time to conduct a telephone interview, convenient to the participant, was set up. Interviews were audio-recorded with the informed consent of the participant. Upon completion of the interview the recording was transcribed and stored at University of Canberra in a secure electronic file. A $50 gift voucher was sent to each participant in appreciation of their input to the project.

Carers who participated in the focus groups also received a Consent form, Information sheet and Complaints form. The Consent forms were signed by the participants and collected by the facilitator at the focus group. The meeting was recorded, transcribed and stored at University of Canberra. A $50 gift voucher was sent to each participant in appreciation of their input to the project.

Service provider participants also made contact with AlzNSW by phone or email. Assessment criteria ensured they had experience in the provision of service to people with dementia and carers who had experienced a hospital stay in the last two years. Participants were issued with a Consent form and Information sheet. The Consent forms were signed by the participants and collected by the facilitator at the focus group. The meeting was recorded, transcribed and stored at University of Canberra. This group was not paid for their contribution to the project.

3.3 Data Collection

Focus groups with carers were conducted in Dubbo and Newcastle followed by 30 in-depth telephone interviews with carers from across NSW. Four focus groups were then conducted with community-based service providers in regional and metropolitan NSW. Finally a validation focus group with carers was conducted to invite carers to make comment on the themes that emerged from the data and share information.

In addition, a third source of data was collected from the records of 19 hospital site visits, conducted as part of the HDS project by the AIHW. The sections in each hospital report focussed on discharge planning and staff perspectives of their relationship with community-based services. Approved pseudonyms for the hospitals were used in the data collection process.
Table 3.1 below summarises the data collection and participants for each component of the study.

**Table 3.1 Data collection – carers and service providers**

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<tr>
<th>Type</th>
<th>Location</th>
<th>Number</th>
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<td>Focus Groups - carers</td>
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<td>Newcastle</td>
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<td>Telephone interviews- carers</td>
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<td>Focus group – carer validation</td>
<td>Bondi Junction</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total participants</strong></td>
<td></td>
<td><strong>71</strong></td>
</tr>
</tbody>
</table>

**Carers**

Carers were used to:

- *Obtain information about the direct experience of service use from hospital through discharge to home*
  
- Determine the met and unmet needs of carers in this experience and
  
- Identify the community service requirements following hospitalisation to ensure quality of life for the carer and the person with dementia and reduce the incidence of hospital readmission and unnecessary placement in residential care.

Table 3.2 outlines the characteristics of the carer focus group participants in Dubbo and Newcastle.

**Table 3.2 Focus groups for Carers**

<table>
<thead>
<tr>
<th>Location</th>
<th>Dubbo</th>
<th>Newcastle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Females</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Aboriginal background</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Relationship to person with dementia:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Adult child</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Son-in-law</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Friend</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Telephone interviews participants were sourced from across NSW and comprised of:

Table 3.3 Telephone interviews with carers

<table>
<thead>
<tr>
<th>Males</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>26</td>
</tr>
<tr>
<td>CALD background</td>
<td>5</td>
</tr>
<tr>
<td>Three conducted through an interpreter</td>
<td></td>
</tr>
<tr>
<td>Relationship to person with dementia:</td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>22</td>
</tr>
<tr>
<td>Adult child</td>
<td>7</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
</tr>
</tbody>
</table>

During the focus groups and telephone interviews carers were asked what community-based services they were using before the person with dementia was hospitalised, what their experience was like and what were the most challenging and satisfying times, including time spent in hospital and on discharge.

Carers were asked whether they accessed services on their return home and if so what those services were. Where they difficult to access? How did they find out about them?

Finally they were asked to share any other aspect of their experience that may help us understand the interaction between home and hospital for people with dementia (See Attachment 4 for semi-structured interview schedule).

A validation focus group of carers was conducted after analysis to compare the findings with the experiences of the validation group members.

The validation focus group membership comprised of:

Table 3.4 Validation Group

<table>
<thead>
<tr>
<th>Males</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>3</td>
</tr>
<tr>
<td>CALD background</td>
<td>2</td>
</tr>
<tr>
<td>Relationship to person with dementia:</td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>1</td>
</tr>
<tr>
<td>Adult child</td>
<td>3</td>
</tr>
</tbody>
</table>
Community-based service providers

Community-based service providers were used to:

- Obtain information about their experience in the care of people with dementia and their carers where the person with dementia had been hospitalised and returned to live at home
- Compare their opinions with that reported by carers

Questions used for these groups can be found in Attachment 5.

Focus groups for service providers comprised of:

Table 3.5 Focus Groups

<table>
<thead>
<tr>
<th>Location</th>
<th>Dubbo</th>
<th>Newcastle</th>
<th>Concord 1</th>
<th>Concord 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>6</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Type of service provision</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Education</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Carer Respite and support groups</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal Advisory and Liaison</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNC, ACAT Tele Health</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Dementia CNC</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Community Service Mgr</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Case manager</td>
<td></td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>GM Neighbour Aid</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Dem Nurse Community Hlth (hospital setting)</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>DBMAS</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>DAS</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>
3.4 Analysis

All data was thematically analysed using a two-staged (seven steps) process. In the first stage, verbatim participant comments or AIHW file notes were paraphrased to capture the key elements of the statements. In the second phase, the paraphrased commentary was hermeneutically analysed to develop meaning using Colaizzi’s framework (Sanders, 2003). Data was analysed separately by two members of the research team and themes were validated in a meeting with the two members and a third member of the team who had participated in data collection and had read all transcripts.

To separate findings from carer and community-based service provider participants and the HDS site visit reports into regional and metropolitan areas, an exercise was undertaken to identify any themes that were unique to geographic location. Following this analysis, the research team agreed that there were no significant differences between regional and metropolitan experiences and therefore the data has not been separated for the purpose of this report.

3.5 Ethics

Ethics clearance was granted by the Human Research Ethics Committee of University of Canberra Project Number 12-172 on 2 October 2012.

3.6 Limitations

Except for basic demographic data collection there was very little quantitative data collected. This means that generalisations to a broader population are not possible however the views and insights provided by participants resonated with the validation focus group and provide deeper contextual descriptions of the hospital-to-home experience.

In-depth telephone interviews were not included in the original project proposal. However due to a low response rate to participation in carer focus groups the data collection method was amended to include in-depth telephone interviews. This method attracted additional participants and added to the richness of the data collected.

Throughout the project there was a propensity for individuals to describe the hospital experience rather than the transition to home experience. While this limited the ability to address important issues related to the period of transition, it did reinforce the findings from the HDS project in this area, and highlighted the need for further research and continued investigation of the experience of people with dementia and their carers in hospital, particularly using qualitative methods of data collection.
4. FINDINGS

This chapter provides an overview of the findings from three sources of data. The first section in this chapter summarises the perspectives of carer participants on the transition from hospital to home for people with dementia.

The second section summarises the perspectives of community-based services participants on the transition from hospital to home for people with dementia.

The third section of this chapter summarises the themes emerging from the HDS project site visit reports.

In the final section, the data from the HDS project is compared with the findings from the participants, with areas of consistency and diversity identified. In the following chapter, the findings are discussed in light of current literature on the transition of people with dementia from hospital to home.

4.1 Carers’ perspectives on the transition from hospital to home for people with dementia

The carers who participated in this study were active in their caring work, whether the person with dementia was living alone or with the carer. All of them were stoic in their responses, with many acknowledging that they would not access services until they felt that they were no longer able to cope.
A service provider described the stoicism of one carer who told her:

_We’ve always managed. ... We will do it ourselves. Thank you very much dear. You can come up and have a cup of tea anytime but no, we don’t want any help._

And another man explained:

_My wife did everything for me for 51 years and I will do whatever is possible for her as long as I can._

One carer reported that she was offered some help in the house but she refused as she felt she could manage. Then she was offered help showering her husband but she refused that as well saying:

_I just kind of managed on my own._

Most participants also acknowledged a sense of great personal sadness when residential care was noted as an option for the future.

The in-hospital experience had a significant impact on carers’ transition home with the person with dementia. Discharge planning and access to services were raised as significant areas that require improvement. Specific themes to emerge from the carer interviews and focus group discussions included:

1. Carers experienced a paradox in hospital: Carer presence was often required as a familiar person to support basic requirements of hygiene, diet, and toileting yet this phenomenon co-exists with the carer often being ignored (by staff) while staff assumed that the person with dementia could recall facts and make decisions.

2. The transition to home is difficult due to inconsistent, and often non-existent, discharge planning, carers feeling judged by some health service providers, and general tiredness from the hospital vigil.

3. Access to services is limited by geographic availability (common to both metropolitan and regional areas), service admission rules such as funding or geographic boundaries, and cost.

4. When at home, social support for the person with dementia and their carer was highly valued drawing on informal networks, especially carer to carer, as well as formal respite care and social services.

Several carers shared stories of being with the person with dementia in hospital, some asked to come in and stay with the person, others felt they should stay to help the staff and others preferred to stay due to their awareness of the person’s response to being in hospital. All carers commented on their contribution to basic nursing care needs such as helping with meals, showers and toileting. At the same time, many reported staff talking with the patient directly about medical care decisions often related to the reason for admission (co-morbidities), and being ignored or having their perspective dismissed/discounted. This was reported as a frustrating experience as it often led to delays in treatments and discharge.

One carer in regional NSW told of the time wasted when staff, who had been told her mother had dementia, repeatedly asked her mother questions about her medical history and spent “three or four hours” searching for records in another hospital, where the mother claimed she had been admitted, when in fact, the event had never occurred.
A service provider reported:

_We’ve (community nurse) gone along to meetings (with hospital staff) and said “you realise this person’s got dementia? And they’ve gone “Oh, that explains it then”._

Discharge planning, when undertaken in consultation with a geriatrician and/or social worker was considered very helpful. However, this experience was rarely reported, with many reports of more abrupt discharge experiences. Several carers reported receiving phone calls from the hospital while at work or on their way to visit to indicate imminent (same day) discharge. In some cases, the person with dementia was packed up and left unattended resulting in instances whereby the person with dementia absconded from the hospital before the carer could arrive to collect them.

**CASE STUDY 1**

Stephen, who cares for his father, told of being phoned by the hospital to say his father was ready to be discharged. Stephen explained that he was at work and could not get to the hospital for two hours. The hospital assured him they would care for his father until then. Half an hour later the hospital rang Stephen and asked “have you picked your father up?” When he responded that he had not they replied “Oh he’s gone missing.” Apparently Stephen’s father had been told that he was right to go home and that the hospital would call Stephen to pick him up but due to the symptoms of dementia Stephen’s father only recalled the fact he “was right to go home”. He left the hospital and was missing for over six hours having travelled 15 kilometres. The son exclaimed “he was in a bit of a mess when we got him back home”.

Geographic and service funding boundaries were very challenging for carers. Carers noted the lack of services near home, particularly rehabilitation services, in metropolitan as well as regional areas of NSW. Service boundaries, particularly when providers strictly interpreted the boundaries, resulted in inflexible service delivery leading to fragmented services for people with dementia and, therefore, service gaps.

Table 4.1 provides details of the specific themes to emerge from the carer interviews and focus groups.
Table 4.1 Carer themes

<table>
<thead>
<tr>
<th>Overarching themes</th>
<th>Carer data themes</th>
</tr>
</thead>
</table>
| Carers experienced a paradox in hospital: Required carer presence as a familiar person to support basic requirements of hygiene, diet, and toileting co-exists with carer being ignored while staff assumed person with dementia could recall facts and make decisions.                                                                 | • Someone familiar needs to be constantly present in hospital to reduce anxiety (and behaviours).  
• Someone needs to be present to ensure adequate nutrition, fluids and medications delivered and prevent removal of tubes/treatments and absconding due to low hospital staffing/interest.  
• Carers did not feel that in acute services staff understood PWD.  
• Carers at times feel dismissed or ignored by a variety health professionals.  
• When staff noted that the person with dementia may have cognitive deficit and consulted carer, then better patient outcome reported and greater carer satisfaction with services delivered.  
• In rare cases, when the carer was acknowledged it resulted in good outcomes for person with dementia.                                                                                                                                                                                                                                                                                                                                                   |
| The transition to home is difficult due to inconsistent discharge planning, carers feeling judged by some health service providers, and general tiredness from the hospital vigil.                                                                                                       | • The medication changes undertaken during hospitalisation did have a positive outcome for some.  
• Reticence for treatment and rehabilitation felt by carers – health professionals not keen.  
• Often no formal discharge process or discussion. Geriatrician assessment in hospital can improve access to services post-hospital.  
• Carer becomes tired by hospital vigil and finds it difficult when PWD is discharged, esp as carer ages.  
• Hospital admission appears to contribute to deterioration in cognitive status – morepronounced with longer hospital stays.  
• Sometimes good discharge plan – seems to be led by social workers.                                                                                                                                                                                                                                                                                                                                                  |
| Access to services is limited by geographic availability (metropolitan and regional issue), service admission rules such as funding or geographic boundaries, and cost.                                                                                                                                          | • The availability of home modifications was variable across all areas with some able to access easily and others waiting years.  
• Access for services in the community is sought at the point when the carer no longer feels able to cope alone or with informal support.  
• Sometimes difficult to get services near home, especially rehabilitation.  
• Carers often bewildered as to what services are accessible and available.  
• In several cases, carers have to ask for specific services.  
• Carers navigate entry into services often by way of an informal process through conversation with other carers.  
• Carer negotiating medication with doctors, chemists, RN in day care services.  
• Fall between cracks for relatively simple nursing care – skin care, oral antibiotics – pronounced if living alone.  
• ACAT re-assessment can lead to new services but access can be delayed due to limited availability in the region.                                                                                                                                                                                                                                                                                           |
| When home, social support for the person with dementia and carer highly valued drawing on informal networks as well as formal respite care and social services.                                                                                                                               | • Respite day services used for social support for PWD and opportunity for carer to run errands.  
• Respite week services used for annual leave, working out of town.  
• Informal support – friends, neighbours and other carers of people with dementia were seen important to continuing to manage care at home.  
• Cultural community groups and support groups provide valued social support services for PWD and carer.                                                                                                                                                                                                                                                                                                                                                   |
Funding rules regarding access included service cross-over which in one case resulted in a service being cancelled when the provider discovers the person with dementia is receiving care under another package, even though the two packages are delivering quite different services.

CASE STUDY 2

Geoff cares for his mother at home. After his mother was discharged from hospital she resumed delivery of her EACH package. During the time of transition to home Geoff sought advice from another source about his mother’s incontinence and, in negotiating the appointment for an assessment, was not asked whether his mother was in receipt of any packages.

Three weeks later the service provider arrived to assess his mother for assistance with her incontinence. Before the provider began her assessment Geoff told her his mother was receiving an EACH.

The provider replied “Oh, EACH package. Oh well then I’m not allowed to be here. I need to go.”

Regarding access to service delivery, many carers would wait until they were struggling to manage their care responsibilities before making contact for services. Other carers noted that services were not offered but knew they would need to access them at some point in time. When carers discover that aged care services, unlike hospital services, require payment, many will carefully consider which services to access, with all reporting access to respite services.

On discharge carers noted that the packages offered, and the requirement to be assessed for what is most appropriate, was a process of waiting, post discharge. Carers waited for an at home assessment, and then, post assessment waited for varying times for the service to commence. People already in receipt of packages pre hospitalisation, found that the services usually continued post discharge. However, the previous service may or may not still meet their current and often changed needs.

Although many carers reported using a range of domestic services, all commented on the value of respite care as well as the social support provided by their community networks.

A service provider reported the help provided by a local church group:

_They used to have a roster to walk one of my ladies (who has dementia) because she had done lots of walking and her husband had a bad heart. And she wanted to walk and pace of an afternoon and he couldn’t keep up with her with his heart._

One carer described the benefits she received from the carer support group, especially the peer support from other members including tips and strategies about how to cope as well as an understanding that “there are other people going through the same thing”.

Another carer spoke about a dementia café, which meets fortnightly, where both she and her husband with dementia can attend. She claimed it reduces the isolation often felt by carers and helps you feel ‘connected’
When asked about respite services one carer responded:

_It was wonderful. The carers were absolutely magic with Mum. It gave me time to go out and just even have a cup of coffee with a friend…...it gave me time to run my business and to be able to concentrate on what I needed to do with it. And it gave Mum someone else to talk to. But the added bonus was that by this stage Mum’s mobility was so deteriorated that it (respite) enabled me to keep her home for another year._

When discussing services they found helpful, carers identified useful and often innovative services including:

- The Top5 carer’s tool for ambulance and hospital
- Provision of computer and computer training to reduce isolation and increase access to home delivery services such as groceries
- Telephone interpreter services and CALD cultural support services

\footnote{The Top5 carer’s tool supports continuity of care for people with thinking and communication difficulties across all care settings. It was developed in NSW Central Coast Local Health District and is currently being trialled around the state.}

### 4.2 Community-based service providers’ perspectives on the transition from hospital to home for people with dementia

The community-based service providers who participated in focus group discussions commented on key areas of carer decisions regarding services for people with dementia, issues related to service access once discharged from hospital and the influence of hospital practices on home-based care. Refer to Table 4.2 for a full description.

While carers are seen by providers to lead the decisions around service use, providers noted that many carers will not pursue recommended services due to concerns about potential residential aged care facility placement, the costs of services exceeding available income, especially for those on limited income or pensions, and the stigma associated with having dementia. When carers are evaluating which services to use, they often rely on other carers’ advice and recommendations.

All of the service providers agreed that service provision was highly complex and that the complexity could be attributed to the range of packages and services available from private, state and Commonwealth providers. Understanding the ‘rules’ for these services was important and many providers were not familiar with the ‘rules’ and processes for other services. The lack of coordination was identified as a significant factor in the fragmentation of services for people with dementia living at home. There were some examples where coordination and positive discharge outcomes were achieved through regular weekly (and in one case daily) meetings of community-based service providers/liaisons and hospital staff or through the appointment of a coordinator role.

The hospital experiences of care and discharge planning were recognised as having a strong influence on the experience of returning home for people with dementia. Providers reported that service access needs to begin early, with people with dementia being prescribed packages that do not require an ACAT assessment e.g. ComPacks.
It was noted that some carers learn about caring practices by observing the hospital nurses. This can usually be beneficial but in one case shared by the providers, the family had restrained the person with dementia into bed to prevent self-harm, based on their experience of hospital.

While the providers noted that carers are encouraged to lead on the selection of community-based services for the person with dementia, the providers consistently voiced their concern that people with dementia and their carers would not be able to manage consumer-directed care services without the support of a dementia trained case worker. The current system of services is fragmented, with multiple providers, boundaries, and overlap, requiring continuous negotiation. It was agreed that careful guidance will be required to assist carers through the process of selecting and evaluating the services that meet their needs.
### Table 4.2 Community-based service providers

<table>
<thead>
<tr>
<th>Overarching themes</th>
<th>Community-based service provider data themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers lead decisions about community-based services and these decisions are often</td>
<td>• Resistance to community-based services is related to fears about (1) eventual residential aged care facility placement, (2) costs associated with services, (3) stigma associated with having dementia.</td>
</tr>
<tr>
<td>influenced by fears about residential aged care facility placement, service costs</td>
<td>• Often carers don’t know what is available to them. Others do know but believe they are coping well enough and not ready to accept services offered to them.</td>
</tr>
<tr>
<td>and stigma, as well as information gained from discussions with other carers.</td>
<td>• Carer support group is a great source of information about services and support for carers.</td>
</tr>
<tr>
<td>Fragmentation of community-based services related to service provision time limits</td>
<td>• Resistance to including PWD in rehabilitation or recovery programs is related to (1) professional judgement about possible clinical improvements by service gatekeeper and (2) often with significant waiting times prior to service commencement.</td>
</tr>
<tr>
<td>and delays due to oversubscription of services can be addressed through high-level</td>
<td>• Can still be gaps between time-limited state services and beginning of over-subscribed Commonwealth services.</td>
</tr>
<tr>
<td>service coordination.</td>
<td>• Having accessed one service programme can exclude access to other services but unknown to carers of PWD and some service providers.</td>
</tr>
<tr>
<td>Hospital experiences, including discharge, influence the home-based experience.</td>
<td>• Assessment for home-based services need to be done at home, therefore TACP/ComPacks recommended for transition while await assessment.</td>
</tr>
<tr>
<td></td>
<td>• Dementia trajectory requires regular re-assessment.</td>
</tr>
<tr>
<td></td>
<td>• Improved coordination of services is required to manage segmentation of services in metropolitan and regional areas. Amalgamation under remote LHD is an example of significant improvement.</td>
</tr>
<tr>
<td></td>
<td>• ACAT delays and service provision delays lead to crisis and re-admission (more commonly reported in metropolitan than rural regions).</td>
</tr>
<tr>
<td></td>
<td>• Case conferences held in hospital and including community-based providers leads to good outcomes for PWD.</td>
</tr>
<tr>
<td></td>
<td>• Hospital focus on bed management sometimes limits quality of discharge planning.</td>
</tr>
<tr>
<td></td>
<td>• Discharge planning may be non-existent, assumes previous services will still be immediately available.</td>
</tr>
<tr>
<td></td>
<td>• Hospital staff unfamiliar with package provisions may negotiate packages that don’t really help on discharge.</td>
</tr>
<tr>
<td></td>
<td>• Some workers can cause harm – incorrect advice, accelerated behaviours, poor care, lack of connection to required services.</td>
</tr>
<tr>
<td></td>
<td>• Hospital practices may be reproduced at home by carers (families) who believe what they observed in the clinical arena to be the way to deliver care (families) eg physical restraint.</td>
</tr>
<tr>
<td></td>
<td>• Challenges of dementia in hospital magnified when PWD is younger – harder for the hospital staff to believe person has dementia so errors made due to assumption of understanding, exclusion of carer.</td>
</tr>
</tbody>
</table>
4.3 NSW Hospital Dementia Services project site visit data related to discharge and community-based services

The data from the 19 hospital site visit reports generated from the HDS project were reviewed, with a focus on the discharge planning and community relationship sections. The site visits were undertaken in 2011. The key issues arising from the HDS data are outlined in Table 4.3.

- The availability of short-term home-based care supports discharge from hospital.
- The Aged Care Assessment Team (ACAT) assessment at home, rather than in hospital, requires significant planning regarding timing of service provision, with risk of no follow-up.
- Rehabilitation and other transition services may exclude people with dementia.
- Availability of emergency respite may reduce hospital admissions.
- Regular (usually weekly) coordination meetings between community and hospital stakeholders, with a focus on discharge planning, improved outcomes.

Hospital staff responsible for discharge planning often used community-based services that had open admission requirements such as ComPacks, Meals on Wheels, dementia day care to support discharge of people with dementia while they awaited an Aged Care Assessment Team (ACAT) assessment. The ACAT assessment is required to access a range of government provided packages designed to support older people to stay at home. The Emergency Department (ED) staff would also use community-based services, particularly ComPacks, to discharge people with dementia home.

While the ACAT assessment at home provides clear evidence to support requests for services, there is significant planning required regarding timing of the assessment. Many people with dementia who are discharged from hospital require immediate home support to prevent re-admission. At the site visits, respondents indicated that once the ComPack service ended, usually in six weeks, the person with dementia and carer were often still waiting for the ACAT assessment, significantly increasing the risk of hospital readmission. Further to this, the carer often coordinated home-based services once discharged, because the hospital did not follow-up. Many providers, as noted previously, reported concern regarding a gap between timing and subsequent provision of services.

Access to rehabilitation services, both home and facility based, was rarely considered for people with dementia. In one on-site interview, providers of transition care programs were genuinely surprised by the suggestion that people with dementia may require their services following hospital discharge. Their resistance appeared to be based on the assumption that people with dementia are unable to follow instructions about self-care.
Table 4.3 Key issues arising from HDS data

| The availability of short-term community services supports discharge from hospital | • The availability of community services did not limit discharge e.g. there were enough ComPacks in general.  
• There is a dementia specific day care in most areas.  
• Use HACC and ComPacks as interim while wait for EACH and CACP but when these run out, many people with dementia have no services until other programs begin 2 to 6 months later.  
• ComPacks are commonly used post-hospital as readily available and don’t require an ACAT assessment to begin service – limited by six week timeframe for package. |
|---|---|
| The ACAT assessment at home, rather than in hospital, requires significant planning regarding timing of service provision, with risk of no follow-up | • The availability of home-based ACAT assessment is variable, with waits up to three months in some areas. Assessment required before access to some packages.  
• Aged care services are brokered from multiple private providers, requiring continual management and quality review.  
• There is a long waiting list for long term loans on equipment.  
• Larger centres have a central coordinating service – Regioncare (pseudonym) – central intake and common database for all health and community services.  
• Funding arrangements can reduce opportunities to share resources, complicate service coordination.  
• The definition of ‘acute’ can delay ACAT assessment for community-based services while person with dementia is in hospital. |
| Rehabilitation and other transition services may exclude people with dementia | • People with dementia are not routinely considered for Transitional Aged Care Packages (rehab focus).  
• Hospital staff working with those providers of ComPack services who will not accept people with dementia. |
| Availability of emergency respite may reduce hospital admissions | • In some areas, and where it’s available, ED is high user of emergency respite beds in the community.  
• Use ComPacks to discharge from ED.  
• Use community—based respite beds who accept hospital patients with a clear exit plan. |
| Regular (usually weekly) coordination meetings between community and hospital stakeholders, with a focus on discharge planning, improves outcomes | • Hospital staff often unaware of community-based dementia specialists, including DBMAS specialists.  
• Most hospital staff noted that there was a good working relationship between hospital and community services.  
• Including an ACAT delegate and/or discharge planner on MDT perceived to speed up assessment process and facilitate discharge home  
• In small communities, the hospital is also the community health centre, promoting great networks across services. When there is not a forum for regular meetings between hospital and community staff, care becomes fragmented.  
• MDT meetings used for hospital avoidance in smaller communities.  
• Effective transfers rely on relationships between hospital and community-based staff, this is especially important when there are not adequate packages available so need bespoke solutions.  
• One community implemented a central intake position to manage referrals but not budgeted. |
ED staff would refer people with dementia to emergency respite care rather than admit to hospital when available. While these referrals required some short-term medical intervention, hospital admission was considered a last resort unless medically required.

It was consistently noted in the site visit reports that when there was strong communication between hospital staff, including discharge planners, allied health services, and geriatricians (when available), and community-based service providers, people with dementia had earlier access to appropriate services. The communication took the form of weekly, or in some cases daily, team meetings, and via professional networks developed over a long period of time, and personal informal networks. Networking, formally and informally, was visible in smaller communities. When the communication was reduced, due to personal capacity or lack of networks, reports of service access problems were more common.

4.4 Community-based services 2011 (HDS) to 2013 (current study)

Many community-based service programs have strict rules for admission, aiming to manage the limited resources, but this had the unintended consequence of service fragmentation and reduced access, for people with dementia. The fragmentation of services emphasized by community-based service providers in this study is consistent with the HDS data collected in 2011. The value of networks, both formal and informal, between hospital staff responsible for discharge and community-based service providers continues to be critical to discharge. However, when people with dementia are outside the boundaries of the hospital or community-based services, care planning becomes more complex as cross boundary networks may not be as robust. Centralised coordination was explored in some HDS sites, and continues to be considered by many providers as a possible solution to the issue of fragmented service provision.

The most common hospital staff community service referral was to ComPacks, which has limited admission requirements. Some people required other services, but access was challenging. When services were available, there is evidence that people with dementia were not always admitted. The findings in 2011 and 2013 indicate that it is unlikely that people with dementia will be offered transition care packages (rehabilitation) and in one NSW region in 2013, some ComPack service providers were also refusing to admit people with dementia.

In the current study, community-based service providers emphasized that even when services are recommended, the person with dementia or the carer may not accept those services. There were many reports of people with dementia agreeing to have home-based services, either while in hospital or during the home-based ACAT assessment, but when the providers called to make arrangements to visit, the person with dementia would deny access and/or the requirement for service resulting in subsequent cancellation of the service.

CASE STUDY 3

Maureen has dementia and lives alone. She was receiving a community support package, arranged by her enduring guardian, her daughter Sue, but did not like the “intrusion” of the provider coming in. Maureen rang the provider regularly and said she didn’t want the service, and was told that she would need to put her request in writing. She duly wrote to the provider who cancelled the service, without contacting Sue.
As already noted, other factors that were considered to contribute to poor uptake of recommended services included fears about residential aged care facility placement, service costs and the stigma of having dementia.

Carers in this study indicated initial concerns about residential respite care as being a transition to permanent residential aged care but once they understood the service, there was less fear and these services were used.

While the cost of services was not explicitly identified as an issue by the carers in this study, this area bears further investigation. Many of the carers did express surprise, when they first began using community-based aged care services, that there was a fee associated with most services. The assumption that aged care services were an extension of Medicare-supported health services was common. People on low incomes or pensions may have difficulty managing the costs of community-based services and therefore not subscribe to recommended services.

To avoid experiencing the stigma associated with dementia, many carers expressed a preference to manage on their own. There were high levels of stoicism among the carers interviewed, with many reporting that they drew on informal family and community networks. Many of those who had more experience in the caring role admitted that their stoic attitude may delay access to services but conveyed their bewilderment at the range of services when they did begin to investigate potential options. Carers in this study reported that their best source of advice on services was other carers, and that the carer support group programs were highly valued.

Many of the carers in this study reported unpleasant, distressing and frustrating hospital experiences, demonstrated in extreme circumstances by some who discharged their loved ones against medical advice. The paradox of the required presence of the carer, to provide care that the person with dementia cannot do due to cognitive impairment coupled with being ignored by health professionals who take their presence for granted and proceed to discuss clinical care with the person with dementia, often with negative consequences, was incredibly frustrating for many. This frustration continued years later, with most carer respondents dwelling on their hospital experiences during the interviews.

In the next chapter, the findings from this study will be discussed in the context of the contemporary literature.
5. DISCUSSION

In this chapter, the key findings from the study are discussed in the context of what is already known with recommendations for community-based service provision being proposed. The findings are discussed in five sections. The first section reviews the disease entity known as dementia, illustrating some of the clinical characteristics of the disease that contribute to the complexity of the transition from hospital to home. The second section reviews the experience of being in hospital, emphasizing the paradox presented to carers of people with dementia. The third section reviews the complexities of community-based services including the factors that influence service accessibility. The fourth section reviews the patterns of service use that emerged from the data. The final section brings together the key findings and makes recommendations for the transition from hospital to home for people with dementia.

5.1 Dementia

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s functioning. It is a broad term used to describe a loss of memory, intellect, rationality and social skills. People with dementia can experience depression, anxiety, confusion and disorientation and due to the complex nature of dementia are exposed to risks such as falls, poor nutrition.

The symptoms of dementia can often be exacerbated by the noisy and unfamiliar hospital environment leading to disruptive behaviours that can be challenging for untrained staff. Effective communication is often limited for people with dementia, which reduces their capacity to express their needs and so engage in the treatment process. Furthermore, the unpredictable nature of dementia and the varying degrees of capacity that can exist from one day to the next mean that a person with dementia can appear to be quite lucid and understanding of treatment advice and then at another time unable to follow instructions.

As the incidence of dementia increases with age it is often coupled with other co-morbidities. Consequently, the cause of admission for most people is often unrelated to their diagnosis of dementia. In fact the HDS project found that for 47% of people with dementia who had a hospital stay in a NSW public hospital in 2006-2007 dementia was not reported as either the primary diagnosis or additional diagnosis (AIHW, 2013). This combination of health conditions, whether diagnosed or not, can result in longer hospital stays with a consequent negative impact on their physical and emotional wellbeing. AIHW (2013) states people with dementia in NSW stay twice as long in hospital as those without dementia.

5.2 Hospital paradox for people with dementia and their carers

Most of the carers who participated in the study experienced a paradox in hospital: their presence as a familiar person was required by (nursing) staff to support basic activities of hygiene, diet, and toileting while concurrently being ignored by (nursing) staff who assumed the person with dementia could recall facts and make decisions based on their verbal and non-verbal response to questions. Carer participants in this study revisited the distress associated with this paradox as they recounted their experiences in hospital. This distress may be related to carers’ perceptions of the importance of the working relationship with hospital staff and/or to concerns about the risks posed to the person with dementia when their views on issues such as medication are being ignored by some staff, thus potentially impacting on care delivery. Other researchers have established that carers
of people with dementia value relationships with staff in residential aged care (Marquis et al., 2004) and community-based services (Innes et al., 2005), so it follows that the relationship with hospital staff may also be highly valued.

Carers’ reported hospital staff often displayed a lack of understanding about the nature of dementia which may lead to critical incidents that increased length of stay. When patients cannot follow staff instructions or share clinical information and the carer is excluded from such conversations, there are subsequent delays in diagnosis, therapy, increased fall injuries and undiagnosed secondary infections, such as urinary tract or respiratory tract infections. This experience is consistent with other studies that found length of hospital stay is significantly longer for people with dementia compared to people without dementia (Sampson et al., 2009; Sampson et al., 2013; Draper et al., 2011) and that people with dementia are at higher risk of injury and complications while in hospital (Cunningham et al., 2006; Draper et al., 2011; Watkin et al., 2011; Zilani et al., 2011; Bail et al., 2013).

In some areas of NSW, an innovative approach to share information about the person with dementia with the ambulance and hospital staff has been developed. The Top5 carer’s support tool lists the five essential “strategies” that would assist staff to provide person-centered care for, and communication with, the person with dementia. This personalised list was considered by many carers in this study to make a difference and others who heard about the Top5 during focus group discussions felt this could provide a good way of sharing information across sectors.

Nurses are the main contact for people with dementia and their carers while in hospital. For many people with dementia, admission to a general medical or surgical ward was necessary for the diagnosis and treatment. Nurses in these areas are experts in their work area specialty, such as cardiology or oncology or in surgical areas, however, in the main, dementia is not their specialty. These nurses develop routine practices to work with the patients coming in for specialist medical services. But researchers have found that when nurses undertake routine care practices, carers perceive the practices as lacking empathy and are not satisfied with the care delivered, or with the interaction between them and the person with dementia (Cowdell et al., 2010). Nurses themselves report feeling remorseful regarding the low level of care that they provide to people with dementia (Byers & France, 2008; Doherty & Collier, 2009). This situation is often attributed to lack of nurses’ knowledge of dementia (Jones et al., 2006; Poole & Mott, 2003; Moyle et al., 2010; Borbasi et al., 2006). Nonetheless, there is a clear case for investment in professional education and competence for the care of people with dementia in hospital, with an emphasis on working with the carers, and also, acknowledging a patient with a diagnosis of dementia at admission so that appropriate care and treatment can be delivered.
5.3 Complexities of community-based services for people with dementia

Many people with dementia experience a longer length of hospital stay, which means that they are at higher risk of reduced muscle tone (Lang et al., 2010; Zuliani et al., 2011), yet the strongest predictor of discharge is functional status (Heppenstall et al., 2009; Wakefield & Holman, 2007; Zekry et al., 2009). As a result of their longer stay, people with dementia have greater requirements for rehabilitation or transition to home care services. The longer length of stay is not always directly related to clinical need. Rather, social needs or the lack of access to community support and care may impact on the length of stay. The community-based service providers in this study reported that people with dementia rarely access transition care packages, and this finding is consistent with the reports from the site visits undertaken as part of the HDS project in 2011. The need for dementia-specific transition care and/or rehabilitation services was demonstrated in this research. The need, where clinically possible, to reduce the length of stay is critical for the continued well-being for people with dementia.

During this project, the researchers learned about a range of programs funded by the Commonwealth and/or NSW State government. A plethora of programs and providers exist, albeit, many are only accessible following an admission assessment, usually by an accredited ACAT. However, access to services and more specifically, the most appropriate service to meet the needs of a person with dementia and their carer, was often much harder to coordinate than originally assumed.

The discharge planning process was considered by the community-based service providers to be a key element for the transition from hospital to home. This view was shared by the hospital staff who participated in the HDS site visits in 2011. In the HDS site visit reports, discharge planning was often led by a nurse or social worker, either nominated as the discharge planner or responsible for bed management, or allocated the work in their broad role e.g., nursing unit manager. In some hospitals in 2011, staff had developed formal and informal networks with the community that promoted effective discharge planning.

The community-based service providers reported that discharge planning was complicated by assumptions that: services would be immediately available; the packages negotiated are appropriate for the person with dementia and the carer; and discharge will free beds for further admissions. In the HDS site visit reports, hospital staff frequently arranged ComPacks, short term (six week) packages of nursing and domestic support until an ACAT assessment and access to longer-term packages could be arranged.

Carers often expressed quite a different view of their discharge experience, which was similar to the findings of the Hancock et al. (2003) study, where discharge planning, as a concept, was highly valued by hospital staff, community staff and carers, but in reality, all three groups were not fully satisfied with the processes. Carers’ experiences of discharge were variable, with most reporting that they received a phone call in the early morning to inform them that the person with dementia could be collected and brought home that morning. In this study, there was often no, or very little warning, given to carers about imminent discharge. One person reported a positive discharge experience that was facilitated by a hospital social worker. Due to the complex nature of dementia the discharge planning process for people with dementia requires higher levels of coordination, and consultation with the carer, than currently provided. Hospital teams should be encouraged to engage with the process of discharge planning from the point of admission.

Once home, many people with dementia are assessed by the ACAT team to determine their need for longer term packages (or residential care). Both carers and community-based service providers reported that there were significant delays, either waiting for the ACAT
assessment or, once assessed, waiting for services to be available. While there are many programs listed as available, there are often delays due to oversubscription of services. The lack of adequate numbers of high care packages was not geographically specific (e.g. not only regional nor only metropolitan) but more widespread. Further to this, the services that were available were fragmented in terms of timing, geographic boundaries, and specific services provided. The plethora of services from multiple providers was overwhelming for many carers, and managing alone while waiting for services was difficult.

Many of the community-based service providers suggested that people with dementia and their carers should have a case manager and community-based services available in specified regions should be centrally coordinated. This view is supported by a systematic review of community services for people with dementia (Low, Yap & Brodaty, 2011). Previous research found that case coordination improves clinical outcomes and decreases residential aged care facility admission and future hospital use (Low et al., 2011; McDonald & Heath, 2009). In an earlier study by Brodaty et al. (2005) lack of knowledge about available services was identified as a reason for carers not using formal services. Carers and staff require better information about community-based services and their accessibility to ensure appropriate support is provided to meet the needs of people with dementia returning home from hospital and negate the incidence of readmission.

5.4 Patterns of service use by people with dementia and their carers

There is emerging evidence that carers are leading decision-making regarding service use by people with dementia (Parker et al., 2008; Galvin et al., 2005) and those people with dementia who do not have a nominated carer are more likely to be transferred to residential aged care (Karmel et al., 2012), from hospital. The respectful involvement of carers in decisions about service provision needs to be recognized as absolutely critical to positive health outcomes (Galvin et al., 2005).

All carers who participated in this study were making the decisions about service provision for the person with dementia. They adopted a stoic attitude to their situation, and carried responsibility for care of the person with dementia. This stoic attitude is consistent with findings from another Australian study (Parker et al., 2008). However, many carers reported confusion about which services to access and sometimes, once services had been negotiated, the person with dementia would reject the service. Rejection of services appeared to be more common for people with dementia who were not residing with their carer.

Respite services were highly valued by carer participants, consistent with international findings that respite is essential for carers’ physical and emotional health (Peeters et al., 2010). Carer participants also valued social activity for themselves and the person with dementia, with many using informal community groups, club-based social outings, as well as dementia-specific day care services confirming research that established the value of social support for people with dementia and their carers (Routsalo et al., 2009; Moyle et al., 2011).

Most important, and identified by all carer participants, was the support of other carers. Carer participants indicated that their informal networks, including other carers, provided a valued source of information, which is consistent with research by Abbott et al. (2012). Further, the use of carer support networks has been found to have a positive effect on psychological wellbeing and social outcomes, as well as reduce depression and carer burden (Chien et al., 2011).
6. Conclusion and recommendations

The transition from hospital to home for people with dementia and their carers was often influenced by their hospital experiences. Many of the carer participants expressed strong opinions about their negative hospital experiences, with associated feelings of frustration and powerlessness. This study presents a clear case for investment in professional education and competence in the care of people with dementia in hospital that has an emphasis on working with carers.

On discharge, many people with dementia experienced some muscle wastage and associated weakness, requiring a period of rehabilitation. However, it appeared that many of the participants did not experience transitional care. Due to the complex nature of dementia and the emotional and physical stress reported by carers, the need for dementia-specific transition care and/or rehabilitation services was consistently demonstrated.

The discharge planning process for people with dementia requires higher levels of coordination, communication and consultation with the carer, than currently provided. While best practice suggests that hospital teams should be encouraged to engage with the process of discharge planning from the point of admission, this was not the experience of most carers in this study.

Carers were found, in the main, to lead decision-making regarding service use by people with dementia. However, carers and hospital staff required better information about community-based services and their accessibility to ensure a smooth decision making process. The carer’s capacity to manage and direct care at home, is dependent on support by formal and informal networks, and is consistent with the literature from Australia and internationally. In particular, the mutual aid found in carer to carer support was critical in enabling the carer to care for the person with dementia at home. The participants in this study reported that information from other carers was essential to navigate care delivery by multiple service providers.

While recognizing the highly localized nature of the sampling method associated with this study, and therefore the limited ability to generalize from the findings, there are some critical insights gained from the research participants that lead to recommendations for further consideration:

1. Increase provision of dementia-specific education and training for hospital staff.
2. Develop and incorporate valuable informal networks and exchanges, which can exist between hospitals and community-based services, into discharge planning and referral pathways to overcome system demarcation issues.
3. Increase and improve access to post-hospital and rehabilitation services designed for people with dementia and their carers.
4. Begin active discharge planning by multidisciplinary teams for people with dementia on admission to hospital.
5. Continue investment in consumer led case management services to enable timely service access for people with dementia who leave hospital, thereby reducing re-admission rates.
6. Develop innovative systems to support people with dementia and their carers during the hospital stay such as a symbol to represent a patient with cognitive impairment and the Top5 carer’s tool.
7. Expand systems to support people with dementia in the transition across health and community sectors such as the Key Worker Program.
The Interaction between Hospital and Community-Based Services for People with Dementia and their Carers
REFERENCES


Alzheimer’s Australia WA. (2007). *Support needs of people with dementia living in rural and remote Australia*. Western Australia: Alzheimer’s Australia.


NSW Health (2010). *NSW Dementia Services Framework 201-1015*, NSW Government: Sydney


ATTACHMENT 1 – INFORMATION SHEET

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

The Interaction between Hospital and Community-based Services for People with Dementia and their Carers

Alzheimer’s Australia NSW is conducting a research project with the University of Canberra. The research aims to investigate the experiences of people with dementia following discharge from hospital to home (including day stays and Emergency Department), from the perspectives of:

(1) their carers and

(2) local community service providers in NSW.

This research project has been funded by NSW Department of Family and Community Services - Ageing, Disability and Home Care.

As part of this research, we will conduct focus groups across NSW with carers of people with dementia and community-based service providers. The focus groups will take up to one hour and will give us a better understanding of people’s support needs, their experiences of the service system, and how to make it more effective.

We will also conduct in-depth telephone interviews with carers. The telephone interviews will take up to one hour and address the same topics as the focus groups.

During the focus groups and telephone interviews, we would like to take notes and, with your permission, record what is said so that our notes are more accurate. What you tell us will be completely confidential and will not be disclosed to anyone other than the researchers involved in the study, except as required by law. You will not be identified in any of the reports or publications from the research – this means that your name will not be included and that any issues or information particularly identifiable to you will not be disclosed.

Your choice to participate is voluntary and will not affect any services or your relationship with the University of Canberra, Alzheimer’s Australia NSW or any other service providers.

If you agree to be part of this project, please sign the consent form that is attached. You are free at any time to refuse to answer particular questions or to stop being part of the study. A withdrawal form is also attached for you to keep.

If you have any concerns or complaints at any time about your part in the study, you can contact the Ethics Secretariat at the University of Canberra, in writing – list address details, by ringing (02) contact here, or by email: xxxx@canberra.edu.au, quoting this reference number: xxx.

Please feel free to contact me on (02) 6201 2229 or Brendan Moore (02) 8875 4681 of Alzheimer’s Australia NSW if you have any questions or comments at any time during the project. We thank you for your help with this research.

Dr Laurie Grealish
University of Canberra
ATTACHMENT 2 - CONSENT FORM

CONSENT FORM

Research project
The Interaction between Hospital and Community-based Services for people with Dementia and their Carers

You are making a decision whether or not to participate in the research. Your signature indicates that, having read the information provided, you have decided to participate.

Signature of Research Participant  Signature of Witness

(Please PRINT name) (Please PRINT name)

Date Nature of Witness
ATTACHMENT 3 – COMPLAINTS FORM

PROJECT INFORMATION

The following study has been reviewed and approved by the University of Canberra’s Human Research Ethics Committee.

Project title:

The interaction between hospital and community-based services for people with dementia and their carers

Project number: 12-172

Principal researcher: Dr Laurie Grealish

INDEPENDENT COMPLAINTS PROCEDURE

1. As a participant or potential participant in research, you will have received written information about the research project. If you have questions or problems which are not answered in the information you have been given, you should consult the researcher or (if the researcher is a student) the research supervisor. For this project, the appropriate person is:

   Name: Dr Laurie Grealish
   Contact details: University of Canberra
   Ph: (02) 6201 2229

2. If you wish to discuss with an independent person a complaint relating to:
   • conduct of the project, or
   • your rights as a participant, or
   • University policy on research involving human participants,

Please Contact:

Mr Hendryk Flaegel
Ethics and Compliance Officer
Telephone (02) 6201 5220
UNIVERSITY OF CANBERRA ACT 2601

Providing research participants with this information is a requirement of the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research, which applies to all research with human participants conducted in Australia.

Further information on University of Canberra research policy is available in the University of Canberra Responsible Conduct of Research Policy and the Human Research Ethics Committee Human Ethics Manual.
ATTACHMENT 4 – QUESTIONS FOR CARER FOCUS GROUPS AND TELEPHONE INTERVIEWS

UNIVERSITY OF CANBERRA & ALZHEIMER’S AUSTRALIA (NSW)

Question guide for Carers of people with dementia

We are interested in learning more about the interaction between services offered by the hospital and the community for people with dementia. Your experiences of transition between home and hospital and back home can help us in learning more about the strengths and gaps in current services.

1. Please share your experience of deciding to have the person with dementia transferred to hospital? What community-based services were you using at the time?

2. Recalling your hospital-based experience, what were the most challenging moments? The most satisfying?

3. When you come home from hospital, what community-based services did you access? Did you need others that were not accessible/available? What other services would have helped?

4. Please share any other aspects of your experience that may help us understand the interaction between home and hospital for people with dementia
ATTACHMENT 5 – QUESTIONS FOR COMMUNITY-BASED SERVICE PROVIDERS

UNIVERSITY OF CANBERRA & ALZHEIMER’S AUSTRALIA (NSW)

Questions for the community-based service focus group interviews:

1. Introduction – where do you come from and what services do you represent?
2. Can you describe your personal experience of services for the person with dementia and the care when they came home from hospital? What worked? What didn’t work?
3. What are your experiences of working with hospital discharge services?
4. In your view, what might contribute to people ‘slipping through the net’?
5. From your perspective, what would be the ideal process for discharge and continuing support?
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NATIONAL DEMENTIA HELPLINE
1800 100 500

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Cooma*: 02 6452 3961
Canberra: 02 6241 0881
Moss Vale: 02 4869 5651
Wagga Wagga: 02 6932 3095
Wollongong*: 02 9805 0100

WESTERN NSW
Orange: 02 6369 7164

* Younger Onset Dementia Key Worker locations

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