Authoritative information and statistics
to promote better health and wellbeing

The Hospital Dementia Services Project

A study description

HDS PROJECT
Hospital Dementia Services

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Contents

Acknowledgments

Abbreviations

ABS   Australian Bureau of Statistics

AHS   Area Health Service

AIHW   Australian Institute of Health and Welfare

HDS   Hospital Dementia Services Project

NHMRC   National Health and Medical Research Council

Symbols

—   nil or rounded to zero

. .   not applicable

n.a.   not available

n.p.   not publishable because of small numbers, confidentiality or other concerns about the quality of the data

Summary

Background

People with dementia have comparatively high rates of hospitalisation. Their relatively high casemix complexity contributes to longer hospital stays, which has an impact on their physical and mental state. Research shows that well-designed and targeted services have improved the quality of care for people with dementia. However, few studies have investigated patient outcomes using integrated information about health services and aged care provision at the regional level.

Objectives

The Hospital Dementia Services Project aims to inform health practitioners, health and aged care policy makers and planners, and consumers of how system factors influence care outcomes for patients with dementia. It will achieve this by investigating the extent to which different types, mixes and levels of hospital-based aged care and dementia services are associated with patient outcomes (e.g. death, admission to residential aged care) while accounting for provision levels of community-based (i.e. non-hospital) aged care services.

Methods

This project is a mixed-methods study. The study population consists of patients aged 50 years and over who had at least one night in a New South Wales public hospital between 1 July 2006 and 30 June 2007, focusing on patients with dementia. The study involves:

- undertaking a survey of hospitals about their dementia and aged care services
- interviews at selected hospitals to obtain information about hospital- and community-based services and to facilitate knowledge exchange
- linking administrative data sets to obtain information about patient pathways through hospital(s) and post-discharge
- a desk audit of aged care service provision
- multilevel modelling to investigate the extent to which patient-, hospital- and regional-level factors influence outcomes for patients with dementia compared with patients without dementia.

An Expert Panel representing key stakeholders will review findings and provide input throughout the project.

Discussion

Findings will result in recommendations about the types and features of hospital-based dementia and aged care services that produce better outcomes for patients with dementia. High stakeholder engagement will enhance the relevance and usefulness of the findings.

1   Introduction

People with dementia have relatively high rates of hospitalisation (AIHW: Peut et al. 2007). Yet, there is evidence that hospitals can be dangerous and unfriendly places for them. (Kurrle 2006). Hazards include polypharmacy, undernutrition, pressure areas, fall-related injuries, nosocomial infections and deconditioning (Torian et al. 1992; Creditor 1993; Cunningham & Archibald 2006; Foreman & Gardner 2005). Hospitalisation can entail multiple bed moves which may cause distress and exacerbate confusion, agitation and behavioural problems (Cunningham & Archibald 2006). Large and unfamiliar hospital environments are associated with patient disorientation and anxiety(Cunningham & Archibald 2006; Davis et al. 2000; Fleming et al. 2003), and the organisational focus on efficient, cure-oriented treatment often means the particular needs of people with dementia are not addressed well (Cunningham & Archibald 2006; NSW Health 2002). As reflected in hospital statistics (AIHW: Peut et al. 2007), the relatively high casemix complexity of patients with dementia contributes to longer hospital stays and this has an impact on patient physical and mental state (ACEMA (Aged Care Evaluation and Mangement Advisors) 2003; King et al. 2006; Nichol et al. 2000). For these reasons, it is important to understand the relationship between different types of hospital-based services, hospital models and outcomes for people with dementia.

There is evidence that well-designed and targeted services have improved the quality of care for people with dementia (Foreman & Gardner 2005; Corbett et al. 2005; Nay et al. 2000; AIHW: Hales et al. 2006). For example, Corbett and colleagues (2005) found that participation in a care coordination program was related to lower rates of admission to other wards following an emergency department admission. An evaluation of the Aged Care Innovative Pool Dementia Pilot revealed that outreach and community-based specialist dementia services reduced the use of hospitals by people with dementia, leading to improved patient outcomes, and post-hospital accommodation outcomes proved sensitive to the availability of high-level home care (AIHW: Hales et al. 2006). While promising, studies in the area have generally either focused on the influence of specific interventions or been observational. Few studies have systematically examined the impact of hospital-based dementia and aged care services on patient outcomes while taking into account patient level factors, such as age, sex and cultural background, and regional factors, such as the availability of community-based services.

The interface between the hospital and aged care systems has attracted considerable attention for service development, yet hospitalisation for those with dementia remains strongly associated with subsequent admission to residential aged care. People with dementia are relatively high users of residential aged care and often require high-level care (AIHW: Peut et al. 2007). Previous analysis of Aged Care Assessment Program data has indicated that assessment in hospital is more than three times as likely to result in a recommendation for residential care than an assessment elsewhere, having controlled for a range of factors, including jurisdiction, client dependency, care availability and co-residence, living arrangements and medical conditions (Lincoln Centre 2005).

A major challenge for dementia care research is to ensure pertinent outcomes are translated into appropriate and effective policy and practice to improve quality of care. Knowledge translation may be defined as 'a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health,

provide more effective health services and products, and strengthen the health care system' (Canadian Institutes of Health Research 2009). Effective strategies include collaborating with key stakeholders to receive expert advice, building the capacity of stakeholders to implement change, and ongoing relationship building with stakeholders to allow issues to mature and evolve. Knowledge translation and exchange is a major focus of this study to ensure that the results are relevant, useful and practical for hospitals and patients with dementia.

Objective

The project's overall objective is to inform health practitioners, health and aged care policy makers and planners, and consumers of how system factors can influence care outcomes for hospital patients with dementia. Specifically, it will examine the associations between patient outcomes and levels of hospital-based aged care and dementia service provision, while taking into account provision levels of community-based aged care services (i.e. home care and residential aged care).

This will be achieved by addressing four specific aims.

- First, we will develop a profile of hospital-based aged care and dementia services that will describe the key operational aspects of different hospital-based service models for patients with dementia (Aim 1).

- Second, we will map the provision of home and residential aged care services in regions across New South Wales to obtain a measure of regional service provision (Aim 2).

- Third, we will profile and compare hospital stays and post-discharge outcomes for patients with and without dementia by hospital, region, aged care and dementia service level and overall (Aim 3).

- Fourth, we will examine the associations between different types and levels of hospital-based dementia and aged care services and patient and hospital outcomes, while taking into account regional factors such as home care residential aged care provision levels and patient characteristics (Aim 4).

2 Method

Underlying study design

Four major research design features underpin this project. These are:

- The use of both quantitative and qualitative techniques to yield findings that are broader in scope and richer in meaning than if only one approach is used (Myers 2000).

- The use of existing administrative data through the application of innovative data linkage methods.

- The use of multilevel (i.e. hierarchical) analyses to allow research to distinguish between patient effects, hospital effects and regional effects (Access Economics 2005; Snijders & Bosker 1999).

- High stakeholder engagement through an Expert Panel comprising the research team and partners representing service providers, funding bodies and consumers that will provide guidance and multiple perspectives at all stages. This critical design element will ensure the relevance and usefulness of results and findings and commitment to dissemination.

These features are integrated to meet the objectives using four streams of work. Figure 1 graphically depicts the study's overall design.

Setting

The project focuses on patients and hospital services in New South Wales (NSW). NSW is Australia's most populous state and has a large and diverse target population covering metropolitan, regional, rural and remote areas, with a range of hospital-based dementia services and variations in the levels of supply of local community-based aged care services. One in three people with dementia in Australia reside in NSW (Access Economics 2005) (over 73,000 people between 1 July 2006 and 30 June 2007), and hospital use by people with dementia is high. Consequently, NSW provides both system and population diversity and a sample size of sufficient statistical power to detect small effects for our main research questions.

Study populations

The person population of interest is patients aged 50 years and over who had at least one night in a NSW public hospital between 1 July 2006 and 30 June 2007 and who were also discharged from a NSW public hospital in 2006-07. Both people with and without dementia are included to allow comparisons. People are identified as having dementia using clinical coding of dementia in hospital admitted patient data for hospitalisations ending between 1 July 2005 and 30 June 2007, noting that a diagnosis of dementia is only recorded if it contributes to the length of stay in hospital and/or cost of treatment and care. For these people, patient level hospital data for both public and private hospitals will be included in analyses to allow a full exploration of people's use of hospitals over time.

The scope of the study includes publicly funded hospitals that were operating in 2006-07 in NSW, Australia. At that time, just over 220 public hospitals operated in eight Area Health Services (AHS) across NSW.
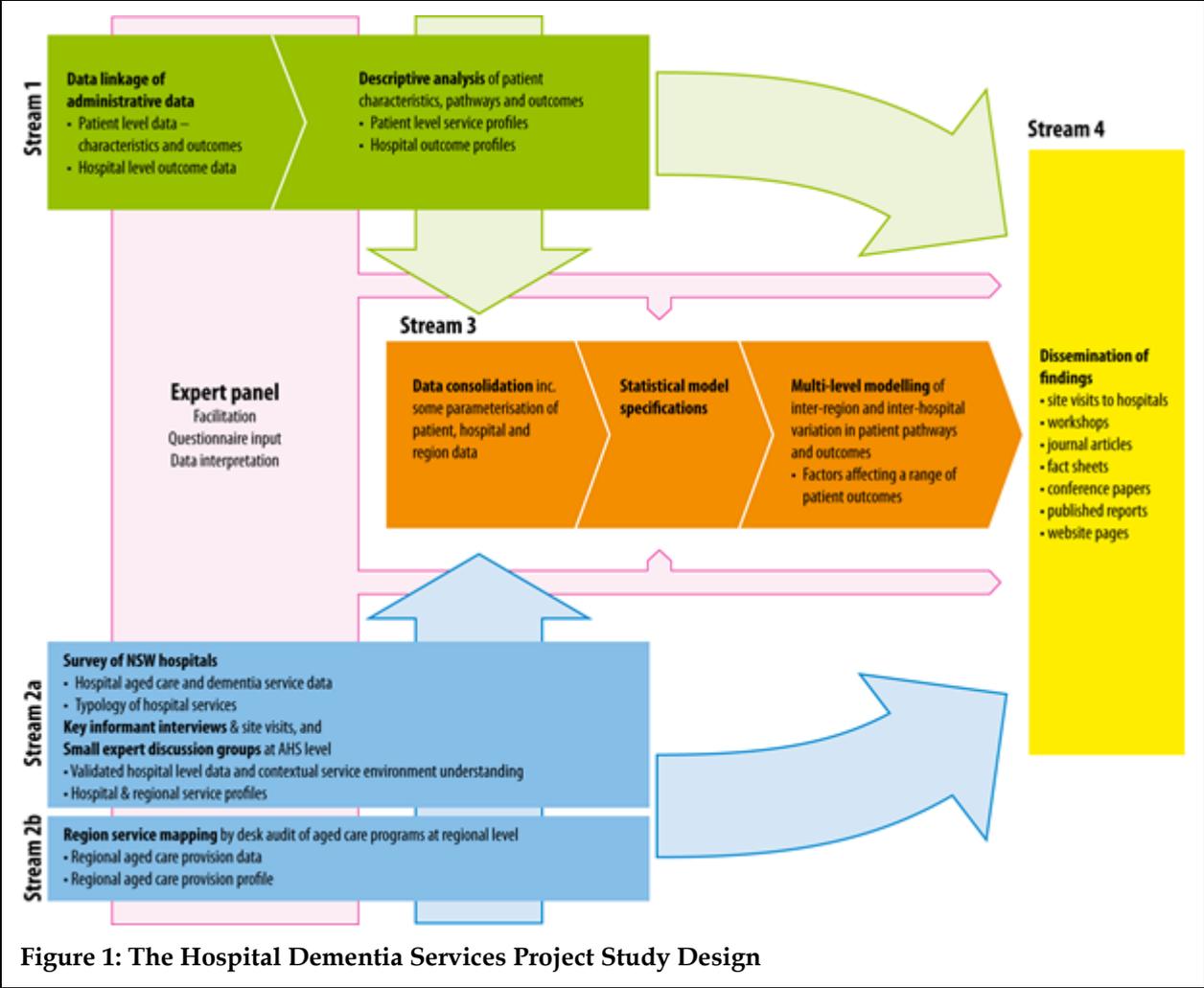
Figure 1: The Hospital Dementia Services Project Study Design

Ethical approval

Institutional Ethics Committee approval was obtained from the NSW Population and Health Services Research Ethics Committee, the Australian Institute of Health and Welfare Ethics Committee, the University of NSW and University of Canberra Human Research Ethics Committees, and 19 Site Specific Approvals that together covered all of the public hospitals in NSW.

Analytic methods and data sources

Aim 1: Describe hospital services and models

Data about hospital-based services has been collected in a survey of NSW hospitals, following the methodology of the National Survey of Hospital Aged Care Services (Gray et

al. 2002). This instrument was expanded to include detailed dementia specific items such as the availability of special care suites, local dementia policies, staff specialising in dementia care. This survey was completed by key hospital informants such as directors of aged care and/or psychiatry services.

A mail survey was conducted, with a shorter general survey form sent to hospitals with no dementia-specific or aged care services and more detailed forms sent to hospitals with aged care or dementia-specific services. Information on hospital websites and consultation with relevant research governance officers was used to identify the appropriate survey form; specific questions on the forms were then used to confirm this choice or to instruct the hospital to obtain the more relevant form. Examples of services about which data was collected include 'hospital-in-the-home' style services, dedicated aged care teams with dementia experience based in the hospital emergency department, and dedicated sub-acute beds designed for the safe management of patients with dementia-related behavioural symptoms.

The Expert Panel was convened to select hospitals for key informant interviews. Selection was based on expert review of survey results and hospital profiles from analysis of routine administrative patient data. The final selection of fieldwork sites included hospitals from each Area Health Service (AHS) and consisted of hospitals from urban and regional settings, and hospitals of different sizes and different service profiles.

Fieldwork at each site visit consisted of a range of activities comprising presentation of preliminary HDS data analysis, key informant interviews, tours of relevant hospital facilities and small group discussions. Each fieldwork study team included senior investigators. The aim of site visit activities was to:

- gather additional information on the operation of hospital services and their interaction with community-based services such as home care and residential aged care facilities
- discuss survey results and hospital data (see Aim 3).

Local participants included medical, nursing, allied health and hospital administrative staff as well as community-based service providers and consumer group representatives.

Quantitative results from the survey will be used to develop a profile of hospital aged care and dementia care services across NSW. Informed by the qualitative results from the site visits, analysis of the survey results and hospital-level patient data will be used to develop a hospital service provision classification. The Expert Panel will provide input to and review the methodology.

Aim 2: Measure/quantify the provision of aged care services across regions

A desk audit of regional aged care service provision has been undertaken using routine administrative data sets that contain information about the provision of a range of aged care services. Relevant data will be obtained at the Local Government Areas and mapped to AHS level using concordance in NSW Population Projection Series 1.2009 (use rates and funding per capita) (NSW Health 2009).

Aim 3: Profile and compare hospital stays and post-hospital outcomes for people with and without dementia

Linking existing routine administrative data sets (NSW Admitted Patient Data Collection, Residential Aged Care data, and the Aged Care Assessment Program Minimum Data Set) has created a database of completed patient episodes of hospital care matched to post-hospital use of residential aged services (high- and low-level care) and, for patients admitted to residential aged care, post-hospital functional status. The scope of the database is data from both public and private hospital episodes for the study population (see method). The hospital data contains a unique patient identifier derived by the NSW Centre for Health Record Linkage. Using this identifier, hospital transfers and patient re-admissions can be identified.

Linkage between the hospital, aged care and assessment data sets has followed the protocol developed and used extensively at the Australian Institute of Health and Welfare (AIHW) (AIHW: Gibson et al. 2003; AIHW: Karmel 2004; AIHW: Karmel 2005; AIHW: Karmel & Rosman 2007). Two linkage methods are used: event-based (without name data) and a statistical linkage key (SLK) incorporating name elements. The event-based method identifies more than 90% of transitions from hospital to residential aged care with over 95% accuracy even when patient names are not used (AIHW: Karmel et al. 2008). The SLK-based matching is even more reliable (Karmel et al. 2010; Powierski et al. AIHW forthcoming in 2011)

The linked database will be used for descriptive analyses of hospital stays and patient outcomes on discharge from hospital. The study populations for Aim 3 are:

(i)   patients discharged from public hospitals during 2006-07

(ii) patients newly admitted to residential aged care from hospital (patients who return to residential care after hospital are identified and excluded from the second population).

The group of interest for this research is patients for whom dementia is recorded as contributing significantly to the cost of hospital care on the NSW Admitted Patient Data Collection, that is, patients with a recorded principal or additional diagnosis of dementia. A recorded diagnosis means that a patient was likely to have attracted hospital-based dementia services, if available. Patients with undiagnosed dementia and patients with dementia for whom dementia does not contribute to the cost of care are not a focus of this research. A critical assumption is that patients with dementia access available dementia specific services as required — it is not possible to track whether an individual patient has made use of any available special care services.

It is estimated that in NSW in 2003–04 there were approximately 25,000 hospital episodes with a dementia diagnosis, and approximately 10,000 patients were admitted to residential aged care from NSW hospitals (3,000 to respite care and 7,000 to permanent care) (AIHW: Peut et al. 2007; AIHW: Karmel et al. 2008). Given this level of activity, the linked database allows for many levels of stratified descriptive analysis of data at the patient, hospital and regional levels. Analyses will compare, for example, care pathways and outcomes for patients with a dementia diagnosis compared to those without, by hospital, AHS, Accessibility/Remoteness Index of Australia, and availability of various types of hospital-based aged care and dementia services. Independent variables include patient characteristics (such as age, sex, veteran status, country of birth, dementia diagnosis, other diagnosis groups, region of residence, usual accommodation setting, living arrangement, limitations in activities of daily living, carer availability and characteristics, depending on the analysis);

patient care characteristics (for example, medical or surgical, change in principal diagnosis and care types during hospital stay, procedures undertaken, total length of stay); hospital characteristics (for example, size, casemix descriptors, location). Key outcome variables of interest are patient care outcome indicators (falls, complications, inter-hospital transfer, mortality, waiting for placement); patient accommodation outcome indicators (for example, post-hospital destination, dependency on entry to residential aged care); hospital outcome indicators (such as rates of admission and re-admission, length of stay, rate of discharge to residential aged care). The Expert Panel will provide input to, and review, the descriptive profiles.

In a second round of visits to selected hospitals and AHSs, small expert discussion groups involving clinicians, planners and policy makers will both inform the interpretation of data at regional and hospital levels and provide opportunity to discuss the findings with key stakeholders.

Aim 4: Test for associations between system factors and patient and hospital outcomes.

For these analyses, findings from the hospitals surveys, desk audit of regional aged care service provision and analysis of the linked database will be used to make statistical inferences based on analysis of multilevel statistical models. Multilevel analysis recognises that the individual and the context, as distinct sources of variability, should be modelled as random effects (Snijders & Bosker 1999). Arling and colleagues (2006) have demonstrated its usefulness in a recent analysis of data on residential aged quality. The proposed research will use multilevel linear and logistic regression methods, as applicable for the outcome variables of interest. The specification of models will vary with the hypothesis being tested as this will determine the dependent (outcome) variable/s and study population of interests and thus the available and relevant independent variables. Models will be specified to account for inter- and intra-cluster variation in the analysis of outcome measures in nested data. Up to four levels corresponding to systematic sources of variance are envisaged:

(i) AHS

(ii) hospital classification

(iii) hospital

(iv) patient.

Expert Panel review will occur throughout, initially to help inform the full set of models for analysis, and later to review and comment on model specifications, results and interpretation.

The main focus of statistical inference will be the extent to which level of hospital-based aged care and dementia services may be associated with specified patient and hospital outcomes, and on the degree of influence of other systemic factors. The analysis will control for any possible effects of AHS, regional aged care service level, or inter-hospital variation not associated with dementia specific programs. A statistically significant aged care provision effect, for example, would indicate that the regional level of aged care provision independently influenced patient outcomes. Model construction and analysis will provide for the possibility of inter-hospital variation at each of the hospital service levels. If this effect is significant, it would suggest that local factors modify the impact of hospital-based dementia service level. A core set of parameters for investigations is shown in Table 1.

Table 1: Key parameters of interest and study population

	Population Parameter of Interest	Study Population
1	Hospital admission and re-admission rate for people with dementia	Admitted patients with dementia diagnosis in 2006-07
2	Hospital length of stay	Admitted patients in 2006-07
3	Patient care outcomes (e.g. falls, complications, mortality)	Admitted patients in 2006-07
4	Hospital rate of discharge to residential aged care	Admitted patients in 2006-07
5	Patient dependency level on entry to residential aged care	Patients admitted to residential aged care following a 2006-07 hospital stay
6	Rate of return to living in the community after residential respite following hospitalisation	Patients admitted to residential respite care following a 2006-07 hospital stay

3   Discussion

A key question posed by the Dementia Research Mapping Project, which identified questions that remained unanswered around dementia care, was 'which dementia care option offers the best client outcomes in terms of quality of care and clinical outcomes?' (Bartlett et al. 2006). Findings from this project will address this research gap by identifying if and which types and features of hospital-based dementia and aged care services are associated with better outcomes for patients with dementia in NSW.

It is envisaged that the findings will generalise to other jurisdictions, as NSW offers the required variation in terms of participants and services and the study's design incorporates the levels of in-hospital services and regional aged care service provision. The continual and collaborative engagement of key stakeholders and the Expert Panel throughout the project will ensure that the findings are relevant and useful for policy makers and planners, practitioners, government and non-government organisations and people with dementia.

The findings will also provide information on several other aspects of the relationship between hospital-based dementia and aged care services and patient outcomes. This includes descriptions about the service environments for patients with dementia in NSW hospitals, such as the types and amounts of services available and their links with other community-based services; volume and characteristics of the flow of people with dementia into and out of acute and sub-acute care, to home and residential aged care; and the potential effects of service intervention at different points in patient hospital and post-hospital pathways. Such findings have the potential to serve as powerful inputs into policy and service development at regional, state and national levels and for non-government organisations.

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