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Title: An evaluation of discharge documentation for people with dementia discharged home from hospital – A cross sectional pilot study

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An evaluation of discharge documentation for people with dementia discharged home from hospital – A cross sectional pilot study

Abstract

This study evaluated discharge documentation for people with dementia who were discharged home, against expected discharge criteria and determined relationships between compliance scores and outcomes. This cross sectional study audited discharge documentation and conducted a post discharge survey of carers. There were 73 eligible discharges and clinically significant documentation deficits for people with dementia included: risk assessments of confusion (48%), falls and pressure injury (56%); provision of medication dose decision aids (53%), provision of contact information for patient support groups (6%) and advance care planning (9%). There was no significant relationship between compliance scores and outcomes. Carer strain was reported to be high for many carers. People with dementia and their carers are more vulnerable and at higher risk of poor outcomes after discharge. There are opportunities for improved provision of medications and risk assessment for people with dementia, provision of information for patient support groups and advanced care planning.

Key words

Carers, dementia, discharge planning, general practitioners, transitional care

Introduction and background

Dementia is an increasingly important public health priority globally and its prevalence is increasing rapidly (Prince et al., 2015). Many people with dementia (PWD) live at home and may have developed successful approaches to living with their disease at home. However, when they are admitted to hospital, the unfamiliar environment combined with factors such as pain, additional medication, and surgery can result in exacerbations of confusion and agitation. In addition, during

their hospitalisation, health care professionals may encounter challenges in their management, assessment, discharge planning, and access to post discharge services that result in interruptions in continuity of care in the post discharge period and poor outcomes (Chenoweth, Kable, & Pond, 2015). Previous studies about the transition between hospital and primary care have identified that people with dementia and their carers can benefit from early discharge planning and team meetings with health professionals (Grealish et al., 2013). Deficits in communication and information transfer between the hospital and primary care setting can affect the quality of care after discharge, particularly for people with dementia (Kripalani et al., 2007). The discharge summary is the primary document that contains information for general practitioners (GPs) so they can provide adequate follow up and support services for people with dementia and their carers. If this document does not contain adequate information such as treatment provided during hospitalisation, pending test results and medication changes, then the GP is poorly positioned to maintain continuity of care after discharge from hospital (Cummings et al., 2010; Groene, Orrego, Suñol, Barach, & Groene, 2012; Moore, McGinn, & Halm, 2007; Roy et al., 2005; van Walraven, Oake, Jennings, & Forster, 2010; Ziaeeian, Araujo, Van Ness, & Horwitz, 2012), and tests may be duplicated, medications changed and referrals delayed. In addition, people with dementia are more vulnerable due to their cognitive impairment, and have problems remembering when appointments are due, when to take medications and how to follow instructions provided to them. Many of them have carers or some community support to assist them, however this may not prevent missed appointments or medication errors if the carer does not have adequate information (Bauer, Fitzgerald, & Koch, 2011). In addition, the carers may also have significant health problems and carer burden that may contribute to an increased risk for poor outcomes for people with dementia.

Purpose. The purpose of this study was to evaluate discharge documentation for people with dementia, provided to GPs and patients or their carers, against expected discharge criteria and determine relationships between compliance scores and outcomes.

Study design and methods

This was a cross sectional study that evaluated the proportion of documented criteria items in discharge summaries for general practitioners (GPs), and information provided for carers of people with dementia in the post discharge period. The study was conducted at one acute hospital in a regional area of New South Wales, Australia, over a six month period. Eligible participants were patients with a discharge diagnosis of Dementia (using ICD-10-CM Diagnosis Codes for Dementia) who were discharged home during the study period. Ethical approval was provided by the Hunter New England Health (13/08/21/5.10) and University of Newcastle Human Research (2013-0333) Ethics Committees.

During the data collection period (Oct 2014 - March 2015) there were 313 patients who were discharged with a diagnosis of Dementia (ICD10CM Diagnosis Codes: FO3 Unspecified Dementia or G00.0-F00.9). Of these patients, 240 were not eligible because: 173 were transferred to residential aged care facilities that were not participating study sites, 38 to other hospitals, 11 to inpatient rehabilitation facilities; and 18 to other discharge destinations (including 13 that were deceased). There were 73 (23%) people with dementia who were discharged home or to participating Residential Aged Care Facility (RACF) study sites (1) and eligible to participate in this study. The discharge documentation for these patients was audited using a purpose-developed Discharge Audit Form. The audit form measured demographic data items and expected criteria items in the medical discharge summary and electronic medical record including: cognition and confusion assessments, pending test results, ongoing clinical issues, support required, and information provided to the patient or carer, based on criteria from relevant New South Wales Health Guidelines and Policy Directives (NSW Health, 2006; P. D. NSW Health, Health Services Performance Improvement Branch, 2011). In addition, two specific outcomes were measured: Readmission within three months and presentation to the emergency department within three months.

A post discharge survey form was also mailed out to carers of the 73 eligible participants (to their home address) within one to three months of discharge, to measure outcomes of discharge

planning. Participation was voluntary and consent was implied by completion and return of the anonymous surveys. The survey contained questions about receipt of a copy of the discharge summary, medication instructions, prescriptions, and medications at discharge. There were also questions about appointments or referrals, community services, limitations on activities, home medicines reviews, recommended support groups and follow up with the GP after discharge. The Modified Caregiver Strain Index (Thornton & Travis, 2003) was included in the survey form and results for these carers are reported as scores with a range of 0-26. Carers who score more than seven are considered to be suffering a high level of stress.

Data were analysed using JMP11 (SAS Institute Inc., Cary, NC,). Participants' characteristics were summarised by using means (or medians) for numerical data, and counts and percentages for categorical data. Audit data items were compared by units or wards using Fishers exact test or chi-square tests (significance level set at 5%) to highlight suggestive evidence of differences between units or wards. A compliance score of the items that should have been provided to GPs or patients at discharge was calculated as the percentage of the eligible criteria that were compliant. This was then used as a predictor in a logistic regression for the outcome of representation to emergency department (ED) and readmission to hospital.

Results

The participants: During data collection, eligible patients were discharged from the following wards/units: 17 (23%) from surgical wards, 35 (48%) from medical wards and 21 (29%) from 24 to 48 hour short stay units. Thirty three were male (45%) and 40 (55%) were female and the age range was 56-96 years (Mean 81). There were no significant differences between wards/units for sex and age of participants. Seventy two were discharged home (99%) and 1 (1%) was discharged to a participating RACF. There were four people with dementia (6%) readmitted within 28 days. There were 14 people with dementia (19%) who were readmitted within three months and 19 (26%) who presented to the emergency department (ED) within three months (13 of these were readmitted).

Only 2 were discharged with a primary diagnosis of dementia and 71 had dementia as a secondary diagnosis. Thirty six (49%) had a Mini Mental Score documented and 28 (38%) mini mental scores were < 24/30. Six had a delirium screen conducted and 25 (34%) had Six Item Screener Scores documented and 21 (29%) had scores < 4/6, indicating that these patients were cognitively impaired.

Information provided to GPs

Expected discharge Documentation. Sixty seven (92%) had a medical discharge summary on file, 51 (70%) had a nursing discharge summary and 2 (3%) had an allied health discharge summary. Most medical discharge summaries (66) included documentation about the medical discharge summary being provided to the GP. Table 1 contains data about the information documented in the medical discharge summaries. Diagnosis, estimated date of discharge (required for discharge planning purposes) and allergies or adverse events were routinely documented (>85% of discharges). For people with dementia, only half of the discharge summaries included documentation that they were routinely assessed for confusion, and falls and pressure injury risk (significantly less often in short stay units). Falls and pressure area injury risk assessments include 35 discharges with Waterlow pressure Injury assessments, 32 with falls risk assessments, 4 with patient risk assessments and 3 with specialist aged care assessments. Provision of a week supply of medications at discharge was not documented in a third of discharge summaries, and significantly less often in summaries from short stay units. Many other items were routinely documented in the discharge summary. The results of concern for people with Dementia include only half of them being offered medication dose decision aids (significantly less so in short stay units), and less frequent documentation of information about medications and significant medication changes in short stay units. A significantly lower proportion of referrals to post discharge services and appointments was documented in discharge summaries from medical wards and short stay units compared with surgical wards.

Support required after discharge. Seven discharge documents stated carers were referred to specific types of support groups or education groups including: the memory disorders clinic (3), falls prevention class (2), respite care (1) and dementia services (1). Overall, the lack of contact information for patient support groups and advance care planning is a clinically significant concern for people with dementia.

Pending test/investigation results. Seven (10%) discharges had pending test/investigation results that were documented at the time of discharge and there were 12 (16%) records that contained pending test/investigation results that were not documented, indicating that there were 26% of discharges that had pending test/investigation results at the time of discharge. For 52 discharges this item was not applicable, and there were an additional 2 records with missing data. There were 8 pending test/investigation results flagged to be followed up by the GP.

Ongoing clinical issues. Ongoing clinical issues at the time of discharge were documented in 51 (69%) records. Ongoing clinical issues at the time of discharge included: Cognitive impairment (17), mobility problems (14), falls risk (6), wounds (5) and others (9).

A compliance score of the items that should have been provided to GPs at discharge was calculated as the percentage of the 19 eligible criteria that were compliant. Logistic regression was fit to determine the effect of the percentage point increase in the compliance score on the odds of readmission within three months (n=14). The odds of readmission decreased as the compliance score increased (OR 0.98, p = 0.35) however, this was not significant. This did not change when we adjusted for ward type (OR 0.976, p = 0.303). Logistic regression was fit to determine the effect of the percentage point increase in the compliance score on the odds of presentation to the ED within three months (n = 19). The odds of presentation to the ED decreased as the compliance score increased (OR 0.97, p = 0.12) and when we adjusted for ward type, we found the effect of the compliance score was statistically significant (OR 0.95, p = 0.0308).

Information provided to patients or carers

There was information in most records about the provision of medical discharge summaries (66) and nursing discharge summaries (50) to the patient or carer. There were discharge and follow up instructions/information documented for the patient or carer for all of these discharges (See Table 2), and this documentation was variable ranging from 1.4 - 99%.

It is important to note that there were two items where there were a large number of missing data. Only two thirds of patient's records contained documentation that they were provided with a week supply of medications at the time of discharge, and only half had post discharge requests for medication dose decision aids provided to the community pharmacist. Approximately half had information about indications of complications (signs and symptoms the carer should be concerned about) provided. Only 28% discharges had documentation about carer education provided about management of exacerbations (of confusion), and only one had a home medication review recommended.

Discharges from short stay units contained significantly less documentation about medications provided, requests for medication dose decision aids provided to the community pharmacist, instructions for routine medications and pain management, provision of prescriptions and other risk assessments. Discharges from medical wards contained significantly more documentation about requests for medication dose decision aids provided to the community pharmacist and information about indications of complications provided.

Referrals provided to patients or carers. Discharge referrals and appointments were documented in 26 discharges overall, with 42-46% from medical and surgical wards, but only 12% of discharges from short stay units ($p= 0.0003$). Most appointments were for clinics including outpatients follow up.

There were no requests for GPs to arrange Home Medicines Review.

A compliance score of the items that should have been provided to patients at discharge was calculated as the percentage of the 11 eligible criteria that were compliant. Logistic regression was fit to determine the effect of the percentage point increase in the compliance score on the odds of readmission within three months ($n=14$). The odds of readmission decreased as the compliance

score increased (OR 0.99, $p = 0.33$) however this was not significant. This did not change when we adjusted for ward type (OR 0.98, $p = 0.23$). Logistic regression was fit to determine the effect of the percentage point increase in the compliance score on the odds of presentation to the ED within three months ($n = 19$). The odds of presentation to the ED decreased as the compliance score increased (OR 0.98, $p = 0.14$) and when we adjusted for ward type, we found the effect of the compliance score was of borderline statistical significance (OR 0.97, $p = 0.07$).

Survey data

Although only nine completed surveys were received from carers (response rate 12%), the survey data provide an indication of the information received by carers at discharge. All of these carers reported that they received a copy of the discharge summary. Seven received medication instructions (78%), however four received prescriptions or medications (44%), and only two (22%) had arrangements for medication dose decision aids. Less than half indicated that they received appointments ($n=1$, 11%) or referrals ($n=3$, 33%) and information about community services available to them (33%). Three carers (33%) were concerned about their relative's behaviour in hospital. Only one carer (11%) had a visit by an occupational therapist prior to their relatives' discharge. One carer (11%) responded that they received a visit from a pharmacist to review the medicines in their home after their relative was discharged. All carers reported that their relatives visited their GP within 4 days after discharge. Four carers (44%) responded that they had been recommended support groups and education groups for carers of PWD. Five carers (56%) reported that they were receiving services in their home such as ACAT or TAC programs, personal assistance, respite care and palliative care. For the Modified Caregiver Strain Index, the carers in this study reported scores ranging from 4 to 22 (median =14), and seven of them were scores of seven or more indicating that approximately 78% of carers had high to very high levels of strain.

Discussion and conclusion

Information provided to GPs

GPs were routinely provided with the medical discharge summary (95%), and 26% of discharges had pending test results at the time of discharge. These rates are better than those reported in previous studies (51-77%) (Kripalani et al., 2007), and (47-65%) (Gandara et al., 2009; Kripalani et al., 2007; Roy et al., 2005) respectively. If test results are not identified for follow up by the GP, they may be missed and people with dementia and their carers may not be aware that they are outstanding.

There were some clinically important deficits in the information provided to GPs including risk assessments and the provision of a week supply of medications on discharge. In addition, there were some discharge information items that were of concern for people with dementia and their carers including only half of them being offered medication dose decision aids: referrals to, and appointments for post discharge services and provision of contact information for patient support groups was very low (6%). People with dementia and their carers require adequate support after discharge from acute care and this is a critical area for improving post discharge services and support. Some of these results were significantly lower for discharges from short stay units including risk assessments, provision of medications and dose decision aids and medication information. Given these wards have high patient numbers with short turnover, having clear expectations for discharge of people with dementia is important. Some results were also significantly higher for discharges from surgical wards including referrals to post discharge services and appointments made which indicates potential to address these aspects of post discharge planning for people with dementia discharged from medical wards and short stay units.

The documentation of significant medication changes in this study (86%) compares well to results from previous studies (35%) (Gandara et al., 2009). In addition, ongoing clinical issues at the time of discharge indicate that cognitive and functional assessments and provision of adequate follow up post discharge, are key factors for improving post discharge support and minimising the risk for interruptions in the continuity of care after an episode of hospitalisation. This is critically important information needed by GPs to facilitate continuity of care after discharge (Kable, Chenoweth, Pond,

& Hullick, 2015). It is possible that nursing and allied health discharge summaries might contain some of the more practical information needed by GPs such as functional assessments, and support required for activities of daily living; that would assist them to understand how well the person with dementia and their carer might be able to manage at home. These were not provided as frequently, particularly the allied health discharge summaries, and this may have also influenced the post discharge outcomes for people with dementia in this study (Kable et al., 2015). The evaluation of the compliance scores on outcomes suggested reduced readmission may be associated with increasing compliance, and a significant effect on reduced presentation to the ED after adjusting for ward type. These findings are limited by the small sample size but suggest that further work in this area is indicated.

Information provided to patients and their carers

Most patients and their carers were provided with a copy of the medical discharge summary, and included information such as a nominated carer, instructions for routine medications and health professional contact information for the carer. Ongoing management instructions were provided for 85% and this compares well with previous studies reported provision of follow up plans (2-43%) (Gandara et al., 2009; Kripalani et al., 2007).

Other information was provided less frequently, including a week supply of medications, provision of prescriptions, requests for medication dose decision aids, and information about indications of complications (contingency plan). Clinically significant areas requiring improvement included recommendations for Home Medicines Review by a community pharmacist, and provision of carer education for management of exacerbations. Medication reconciliation has been recommended in previous studies about transitional care (Alper, O'Malley, & Greenwald, 2012; Cummings et al., 2010; Groene et al., 2012; Ziaieian et al., 2012); and is a suitable response following discharge from hospital to assist people with dementia (and their carers) to confirm which medications they should be

taking, the need for devices for administration of medications, checking for potential drug interactions and whether anticholinergics should be discontinued for these vulnerable people. The evaluation of the compliance score on outcomes suggested a reduction in readmissions and presentations to ED associated with increasing compliance, but again this requires further study. The survey data suggest that most people with dementia received a copy of the discharge summary and visited their GP within 4 days. Most received medication instructions and half were receiving services in their home. Although one third of carers were concerned about their relative's behaviour during hospitalisation, only one third received information about community services available to them, and less than half had been recommended support groups and education groups for carers. This is of concern, particularly in view of the very high scores reported for the Modified Caregiver Strain Index by these carers.

Limitations

The study sample was small due to the number of people with dementia who were discharged home instead of residential aged care facilities, other hospitals and other discharge destinations. The response rate to the carer survey was low, and may have been due to high carer strain; there is likely respondent bias. Consequently, these results may not be generalisable to other study settings.

Implications for practice and directions for future research

These results indicate that some aspects of the discharge process were not done consistently for all patients, and some of these people with dementia were potentially more vulnerable due to inadequate information being provided to their general practitioner for ongoing management. The provision of medications, medication dose decision aids, home medicines review and risk assessment for people with dementia, were aspects of this process that present opportunities for clinical practice improvement. The lack of contact information for patient support groups and advance care planning is a clinically significant concern for people with dementia and their carers.

Future research should include special attention directed towards needs of people with dementia discharged from short stay units and post discharge planning for referrals and appointments for people with dementia discharged from medical wards and short stay units.

List of abbreviations

PWD: People with Dementia

GP: General Practitioner

ICD-10-CM: International Classification of Diseases, Tenth Revision, Clinical Modification

RACF: Residential Aged Care Facility

ED: Emergency Department

ACAT: Aged Care Assessment Team

TAC: Transitional Aged Care

Ethics

Ethical approval was provided by the Hunter New England Health (13/08/21/5.10) and University of Newcastle Human Research (2013-0333) Ethics Committees; and was conducted in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans.

Consent to participate

Study information was provided to carers about the post discharge survey. Participation was voluntary and consent was implied by completion and return of the anonymous surveys.

Author contributions

AK participated in the design and coordination of the study, contributed to data collection and analysis, and drafted the manuscript.

DP participated in the design of the study and contributed to manuscript development and revisions.

CH participated in the design of the study and contributed to manuscript development and revisions.

LC participated in the design of the study and contributed to manuscript development and revisions.

AD participated in the design of the study and contributed to manuscript development and revisions.

JA contributed to design of the study and to manuscript review and content revisions.

CO provided biostatistical advice and support and contributed content in the analysis and results sections.

All authors read and approved the final manuscript.

Availability of data and materials

The data will not be shared to protect the privacy of participants and organisations described in this study.

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Declaration of Conflicting Interests

None declared.

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Table 1. Expected documentation in medical discharge summaries – Information for GPs compared by Wards or Units.

Information in medical discharge summaries (Number of applicable records from Surgical/Medical/Short Stay wards/units)	Surgical wards n (%)	Medical wards n (%)	Short stay units n (%)	Total Documented n (%)	P Value
Diagnosis (17/35/21)	17 (100)	35 (100)	21 (100)	73 (100)	1
Estimated date of discharge (14/33/19)	14 (100)	33 (100)	19 (100)	66 (100)	1
Confusion risk assessed, (17/35/21)	8 (47)	19 (54)	8 (38)	35 (48)	0.50
Falls and pressure injury risk assessed (16/34/21)	11 (69)	26 (76)	3 (14)	40 (56)	<0.0001*
Allergies or adverse events (14/33/19)	14 (100)	33 (100)	19 (100)	66 (100)	1
7 day supply of Medications on discharge (11/26/14) †	9 (82)	20 (77)	4 (29)	33 (65)	0.004*
Investigations (14/33/19)	14 (100)	33 (100)	17 (90)	64 (97)	0.12 ‡
Clinical episode of care, Treatment summary and response to treatment (14/33/19)	14 (100)	33 (100)	18 (95)	65 (98)	0.5 ‡
Pathology results (14/33/19)	14 (100)	32 (97)	16 (84)	62 (94)	0.10
Results other diagnostics (14/33/19)	14 (100)	30 (91)	15 (79)	59 (89)	0.14
Significant medication changes (14/33/19)	14 (100)	32 (97)	11 (58)	57 (86)	<0.0001*
Medication dose decision aid offered/provided/arranged (11/25/17)	8 (73)	18 (72)	2 (12)	28 (53)	0.0002*
Given information about medications (15/33/19)	15 (100)	33 (100)	11 (58)	59 (88)	<0.0001*
Discharge and follow up details (13/33/19)	13 (100)	31 (94)	18 (94)	62 (95)	0.67
– referrals to post discharge services (14/33/19)	11 (79)	10 (30)	8 (42)	29 (44)	0.001*
– Appointments made (14/33/19)	10 (71)	7 (21)	6 (32)	23 (35)	0.004*
Care plan (14/33/19)	14 (100)	33 (100)	18 (95)	65 (98)	0.28
Contact information for patient support groups (14/33/19)	2 (14)	1 (3)	1 (5)	4 (6)	0.33
Advance care planning (14/33/19)	2 (14)	3 (9)	1 (5)	6 (9)	0.67

*P value < 0.05 † Large number of missing data items. ‡Fishers Exact test used.

Table 2. Specific discharge and follow up instructions/information for the patient or carer documented.

Instructions/ Information (Number of applicable records from Surgical/Medical/Short Stay wards/units)	Surgical wards n (%)	Medical wards n (%)	Short stay units n (%)	Total Documented n (%)	P value
Carer nominated (17/35/21)	17 (100)	34 (97)	21 (100)	72 (99)	0.58
Medications provided (7 day supply) (14/32/21)	10 (71)	26 (81)	9 (43)	45 (67)	0.013*
Fax sent to Community Pharmacist requesting Medication dose decision aids (13/26/18) †	6 (46)	19 (73)	3 (17)	28 (49)	0.001*
Instructions for routine medications provided (15/34/21)	14 (93)	34 (100)	14 (67)	62 (89)	0.0006*
Instructions for pain management provided (15/34/21)	13 (87)	33 (97)	12 (57)	58 (83)	0.0006*
Prescriptions provided and instructions about when supplies will be used up (13/30/18) †	10 (77)	28 (93)	6 (33)	44 (72)	<0.0001*
Ongoing management instructions provided (therapy/ services, frequency, dates) (13/33/21)	10 (77)	32 (97)	15 (71)	57 (85)	0.02*
Home Medication Review Recommended by Pharmacist (16/33/21)	0 (0)	1 (3)	0 (0)	1 (1.4)	0.57
Information about indications of complications provided (contingency plan) (15/32/21)	7 (47)	24 (75)	7 (33)	38 (56)	0.008*
HP Contact information for the carer provided (16/34/21)	16 (100)	33 (97)	20 (95)	69 (97)	0.69
Carer education provided about management of exacerbations (16/34/21)	7 (44)	8 (24)	5 (24)	20 (28)	0.29

*P value < 0.05 † Large number of missing data items.