Factors associated with family caregiver dissatisfaction with acute hospital care of their older cognitively impaired relative

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ABSTRACT

Background: Older people admitted to general hospitals have a high prevalence of cognitive impairment, but the standard of care they receive has been criticized. A specialist Medical and Mental Health Unit was developed as a model of best practice care, and evaluated in a trial. **Objective**: To identify patient and caregiver characteristics associated with caregiver dissatisfaction with hospital care of cognitively impaired elders.

Design: Secondary analysis of data from a randomized controlled trial.

Setting: An 1800 bed general hospital in England providing sole emergency medical services for its local population.

Participants: 600 cognitively impaired patients aged 65 or older randomly assigned to the specialist unit or standard geriatric or internal medical wards and 488 related caregivers.

Measurements: Patient and caregiver health status was measured at baseline, including delirium, cognitive impairment, behavioral and psychological symptoms, activities of daily living, and caregiver strain. Caregiver satisfaction with quality of care was ascertained after hospital discharge or death.

Results: 462 caregivers completed satisfaction questionnaires. Regardless of assignment, 54% of caregivers were dissatisfied with some aspects of care, but overall 87% were satisfied with care. The main areas of dissatisfaction were communication, discharge planning and medical management. Dissatisfaction was associated with high levels of patient behavioral and psychological symptoms on admission, caregiver strain and poor psychological wellbeing at admission, a diagnosis of delirium, and the relationship of the caregiver to the patient. There was less dissatisfaction from caregivers of patients managed on the specialist Medical and Mental Health Unit compared with standard wards, after controlling for multiple factors. Conclusion: Dissatisfaction was associated with patient behavioral and psychological symptoms and caregiver strain, but was not immutable to efforts to improve care.Key words: aged, general hospitals, satisfaction, dementia, delirium, caregivers

INTRODUCTION

Dementia is becoming increasingly prevalent in developed societies due to the aging population [1]. People with dementia have up to 3.6 times greater risk of hospitalization than age-matched controls [2]. A third of all general hospital acute admissions are of a person over 70 with cognitive impairment (dementia, delirium or both) [2-6]. One estimate is that a quarter of all general hospital beds accommodate someone with dementia [7].

Satisfaction is an important measure of health service performance. The English National Health Service (NHS) Outcomes Framework cites 'a positive patient experience of care' as one of its five domains [8]. Satisfaction is mostly ascertained by self-report, but this is often not possible for patients with delirium and dementia, and family caregiver opinions are taken as an appropriate proxy [9]. There have been high profile reports criticizing the standard of care for patients with dementia in hospital [7, 10]. One study reported that 77% of caregivers were dissatisfied with some aspects of care, but the sample in this study was not likely to be representative [7].

A specialist Medical and Mental Health Unit (MMHU) was developed as a model of best practice when caring for older people with cognitive impairment, based around the principles of 'person-centered' dementia care [11]. This holds that people (and the institutions and systems they work in): must value people with dementia; should individualize care taking account of neurological impairment, physical and mental health, retained abilities, personality, biography, beliefs and preferences; should see problems from the perspective of the person with dementia (in particular, that challenging behavior communicates distress or unmet needs); and recognize the importance of the social environment for well-being, in particular relationships with family and professional caregivers. MMHU staff were trained in this philosophy, and ward medical and nursing leaders encouraged and modelled such behaviors. Specialist mental health nursing and therapy staff were employed to work alongside regular ward staff. A programme of purposeful therapeutic and diversionary activities was provided for those able to take part. The environment was adapted to meet the needs of people with cognitive impairment. A proactive and inclusive approach was adopted towards family caregivers.

The unit was evaluated over 18 months in a randomized controlled trial compared with standard hospital care. One of several secondary outcomes reported from this trial was caregiver satisfaction with patient care, which was compared between settings [12, 13]. 83% of family caregivers were mostly or very satisfied with care on standard wards, increasing to 91% on MMHU [13]. We report a secondary analysis of data from the trial which aimed to identify the patient and caregiver characteristics that were associated with caregiver dissatisfaction, in order to illuminate potential improvements that might better meet their needs in the future.

METHODS

Study population and parent study

We recruited patients admitted as an emergency for acute medical care to a large general hospital in England, who were over age 65 and identified as being 'confused' by Admissions Unit physicians or nurses. 'Confused' is a vague term implying cognitive impairment, but was acceptable and understood by Admissions Unit staff, and was simple enough to identify appropriate patients rapidly in a busy clinical setting, without introducing delay in the admissions pathway. In practice almost all patients had delirium, dementia or both [12, 13], and 93% were subsequently assessed to have a Mini-Mental State Examination score $\leq 24/30$. All recruited patients were retained in the study. Potentially suitable patients were entered on a computerized screening log by MMHU staff, and, if a bed was available on the specialist unit, randomized 1:1 between the unit and standard care in a permuted block design, stratified for previous residence in a care home (a care home refers to a communal residential facility providing 24 hour per day assistance, with or without skilled nursing). The randomization was performed by a web-based algorithm hosted by a Clinical Trials Unit and the sequence was concealed from staff who allocated patients. Standard hospital care comprised six geriatric medical wards and five internal medical wards. We excluded patients with an overriding clinical need for another clinical service (such as critical care, stroke unit or surgery), who did not live within the local health and social care administrative areas (determined by home address postal code), or who were unable to speak English and had no available family or other non-professional translator. For each patient we attempted to recruit a caregiver who was a family member or other informal caregiver who saw the patient for at least an hour every week. Most data for this secondary analysis came from caregivers.

Patients were assessed for mental capacity to consent to participation, following the requirements of the English Mental Capacity Act (2005), using a structured approach (assessing understanding, retention and ability to use information and communicate a decision). If they had capacity they were asked to give written informed consent. Agreement for participation was sought from a family member or caregiver for patients lacking mental capacity [14]. Caregivers also gave written informed consent for their own participation in the study.

Trial baseline information was collected by clinical researchers (nurses and psychology graduates) through interview with the participant, caregiver informants, ward staff, observation, and examination of clinical records. Caregivers were asked to complete a questionnaire regarding their own health and caring responsibilities.

We recorded demographic and social information and a battery of health status measures including delirium (Delirium Rating Scale-Revised-98, DRS-R-98 [15]), cognition (Mini-Mental State Examination, MMSE [16]), behavioral and psychological symptoms (Neuro-Psychiatric Inventory [17]), and dependency in activities of daily living at the time of admission and prior to the acute illness (Barthel Index [18] scored out of 20). Caregiver strain and psychological well-being were measured using the Caregiver Strain Index (CSI [19]); and General Health Questionnaire (GHQ-12 [20]).

One to three weeks after the patient had been discharged from their index hospital admission researchers, who were blind to ward allocation, telephoned the nominated caregiver and completed a satisfaction questionnaire. The questionnaire comprised ten items [7]: overall care, admission arrangements, car parking, nutrition and feeding, medical management, being

kept informed, dignity and respect, meeting the needs of a confused patient, discharge arrangements, and timing of discharge, using Likert-type scales (very/mostly satisfied, mostly/very dissatisfied). Bereaved caregivers were approached to complete the questionnaire six weeks after the date of death, but items regarding timing of discharge were omitted.

Secondary Statistical Analysis

We performed a cohort analysis to compare potential explanatory variables between caregivers who did and did not express dissatisfaction with care. Participants for this analysis comprised all randomized patients and their caregivers for whom we had complete data.

Two sets of analyses were conducted. Firstly, data were dichotomized according to whether the caregiver was satisfied (mostly or very) or dissatisfied (mostly or very) overall with care that the patient received. Secondly, data were split according to whether the caregiver reported being dissatisfied with any aspect of care, omitting items that related to car parking and admission, as these did not reflect ward care.

Descriptive statistics were calculated for those who completed and did not complete the satisfaction questionnaire, and for groups allocated to different ward types (specialist unit, geriatric medical, general internal medical). The statistical significance of differences was calculated using chi-squared, Mann-Whitney or Kruskall-Wallis tests as appropriate. Univariate associations between dissatisfaction and baseline variables were examined using logistic regression. Those with an association statistically significant at P<0.1 were further examined using multivariate logistic regression. Caregiver strain and psychological wellbeing (GHQ-12) were strongly correlated, as were Delirium Rating Scale score and Neuropsychiatric Inventory score, and in each case the more strongly associated of the two

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variables was retained in the final model. We previously showed that ward type (MMHU or standard care) was associated with satisfaction [13], so this was included in the model. Where explanatory variables were in ordered categories (ordinal), including grouped numerical data, we performed a test-for-trend to test the hypothesis that the odds ratio for dissatisfaction varied in a linear fashion with the explanatory variable, by fitting a regression model with the explanatory variable specified as continuous.

Caregiver satisfaction with care was a secondary outcome measure and sample size was determined for the trial primary outcome (days spent at home) [13]). Using the 'ten events per variable' rule, the current analysis had sufficient power to examine a multivariate model with five to six explanatory variables.

Ethical approval

The study was approved by the Nottingham Research Ethics Committee.

RESULTS

Over 18 months between July 2010 and December 2011 600 patients and 488 caregivers were recruited to the study. We were unable to recruit 112 caregivers as 61 (10%) of patients had no identifiable caregiver and 51 (8%) caregivers declined to participate in their own right in the study. 462 (95%) participating caregivers completed the satisfaction questionnaire. Caregivers who completed the questionnaire compared with those who did not were more likely to be a child of the patient (59% vs. 45%) or a spouse (21% vs. 12%). Patients for whom a satisfaction questionnaire was completed compared with those for whom no satisfaction questionnaire was completed were older (median 85 vs. 83 years), more likely to lack mental capacity (80% vs. 67%) and be less physically able (median Barthel score of 8/20 vs. 10/20, higher scores representing greater ability)

310 participants were assigned to the specialist unit, 234 to generic geriatric medical wards and 86 to general internal medical wards. Proportions completing the satisfaction questionnaire, and patient and caregiver characteristics at baseline, were generally similar between ward types. Patients on the specialist unit were more likely to have mental capacity to consent (24% vs.16%), and to have previously been resident in a care home (28% vs. 19%). Patients on general internal medical wards were more likely to be male (60% vs. 45%), and to have a spouse (28% vs. 18%), and length of hospital stay was shorter (median 9 days vs 12 days). None of these differences was statistically significant (table 1).

Fifty-nine of 462 (13%) caregivers expressed dissatisfaction with overall care and 249/462 (54%) expressed dissatisfaction with at least one aspect of care. Caregivers were most likely to be dissatisfied with being kept informed (n=48/459, 34%), discharge arrangements

(n=44/414, 29%), and the management of medical problems (n=46/461, 24%). These features were also most strongly associated with overall satisfaction (table 2).

Univariate associations with dissatisfaction

Caregivers were more likely to be dissatisfied with overall care if the patient lived alone (odds ratio, OR, 1.97, 95% Confidence Interval, CI, 1.04-3.73), had DRS-R-98-defined delirium (or delirium superimposed on dementia) (OR 1.83, 95% CI 1.01-3.32) or was experiencing high levels of behavioral or psychological symptoms on admission (top quartile vs bottom quartile OR 3.81, 95% CI 1.55-9.35). Dissatisfaction was also significantly associated with caregivers experiencing high levels of strain at admission (OR 1.84, 95% CI 1.03-3.26), poor psychological wellbeing on admission (OR 3.87, 95% CI 1.71-8.79), or the informant being a son or daughter (OR 2.50, 95% CI 1.08-5.77). There was a significant association with type of ward to which the patient had been admitted (geriatric medical ward OR 2.04, 95% CI 1.09-3.82; general internal medical OR 2.58, 95% CI 1.23-5.42, compared to MMHU; table 3).

Multivariate associations with dissatisfaction

In multivariate analyses, high levels of behavioral and psychological symptoms (top quartile OR 2.9, 95% CI 1.1-7.7), and poorer caregiver psychological wellbeing (OR 2.6, 95% CI 1.0-6.6) remained strongly associated with dissatisfaction. Including ward type in the model had little impact on the effect size for associations with covariates, but ward type was independently associated with dissatisfaction in overall care (geriatric medicine OR 2.4, 95% CI 1.2-4.8; general internal medicine OR 3.0, 95% CI 1.3-6.8, compared to MMHU) (table 4).

Associations with alternative definition of dissatisfaction

Similar associations were observed in analyses for caregivers who were dissatisfied in any aspect of care, except caregivers of patients with delirium (or delirium superimposed on dementia) were less likely to be dissatisfied (OR 0.63, 95% CI 0.43-0.92) and their dissatisfaction was associated with lesser physical disability in patients (Barthel Index 16-20 OR 2.18, 95% CI 1.14-4.18; table 5).

DISCUSSION

Fifty-four per cent of caregivers of cognitively impaired older people were dissatisfied with some aspects of hospital care, but 87% stated they were mostly or very satisfied with care overall. Over a third were dissatisfied with how well they were kept informed, and a quarter was dissatisfied with the management of medical issues and discharge arrangements. Dissatisfaction was associated with high levels of behavioral and psychological symptoms in the patient at the time of admission, caregiver strain and poor psychological well-being, nature of the relationship, and a delirium diagnosis. Dissatisfaction was less when the patient was managed on a specialist Medical and Mental Health Unit rather than a standard ward after controlling for multiple factors.

This study was embedded in a large randomized controlled trial, and was the first study to examine caregiver satisfaction in a setting where deliberate attempts had been made to improve patient and caregiver experience. Person-centered care was practiced as standard and efforts were made to be more inclusive of family caregivers [11]. Explanatory variables, including ward assignment, were collected prospectively, thus, protecting outcome assessment from bias. Participants comprised consecutive patients potentially suitable for a Medical and Mental Health Unit and as such were a representative sample of cognitively impaired older people admitted to a general hospital and their caregivers.

This study had limitations. Family caregivers are usually only present for a small part of the day, and in this population, patients were often unable to recall details of what care they had received. Family caregivers therefore represented at best partial observers of the quality of care, and their views may not have reflected care actually received [9]. Moreover, they were not blind to ward allocation and opinions may have been biased by the knowledge that the

patient was cared for on a specialist ward. Their experiences may have been influenced by expectations, news reports, and previous experiences in hospital [21]. Ascertainment of satisfaction is controversial [22]. Social desirability bias is common when questionnaires are used, but in this study dissatisfaction was expressed when specific aspects of care were questioned. In the comparison between ward types, there is little reason to believe that interpretation of questions, or desirability biases, will have acted differentially. Despite the study size, some of the analyses in the current study lacked precision, indicated by wide 95% confidence intervals on effect sizes, as the sample size was determined for the primary outcome measure of the main trial [13]. We had no data on incident delirium, other complications, or process measures that might have further explained dissatisfaction. The study took place in a single hospital, and findings may not apply elsewhere. The specialist ward was located in the same hospital as the comparison wards, raising the possibility of 'contamination' or spread of practices between wards. All wards worked under considerable operational pressure. All staff had access to general dementia awareness training, but did not benefit from specific additional staffing or training, or the environment, leadership and culture-change initiatives that characterized the MMHU. Occasionally mental health nursing and medical staff would assess patients on request on other wards and provide advice so long as they were not part of the clinical trial. Some nursing, allied health professionals and medical staff worked across wards to cover shortages elsewhere, during out-of-hours work, due to rotational posts (such as junior doctors) or allied health professionals whose contracted time was not exclusively on MMHU, but the extent of this was small.

Satisfaction with hospital care has been studied in a wide range of contexts. In the United Kingdom [23] and the United States of America [24] large surveys are conducted with all patients discharged from hospital, to assess satisfaction with a variety of outcomes, including

communication with health professionals, medications, pain control and discharge planning. In general, most patients are satisfied with healthcare. Patients with dementia may be included in these surveys, but there are no questions to identify them, and in many (or most) cases they will not participate because of memory and other impairments [9]. There has been relatively little previous systematic study of caregivers' experiences of general hospital care for people with cognitive impairment [25], but one study concluded there could be a disparity between caregivers' and staff members' ideas of what constitutes quality care, with lack of information sharing identified as a key factor in caregiver dissatisfaction [26]. Literature that has considered hospitalization and the needs of relatives more generally, has highlighted the disruption to family members associated with a prolonged hospital stay [27], the need to determine 'hospital rules' and then follow them [28], and the feelings of disempowerment that can arise from the experience [29]. Family members also made judgments about the quality of care [30], the ability and suitability of individual members of staff [31], and worried about what might be happening in the hospital when they were not there [32]. Expectations of caregivers can be high, and may be unrealistic [21]. Caregivers frequently report that communication with ward staff is inadequate [7, 21, 25, 32-36]. Behavioral disturbance in patients has long been associated with poor psychological health in caregivers [37, 38, 39, 40]. Quality of care, behavioral disturbance, caregiver strain and dissatisfaction are likely to have a complex interrelationship. The association between a delirium diagnosis and dissatisfaction has not been previously reported, but may reflect this interrelationship, given its association with severe illness, sudden change in cognition, and severe symptoms such as drowsiness and psychosis [6, 40]. There is evidence indicating that many aspects of hospital care for patients with dementia are unsatisfactory [7, 10], but previous studies have highlighted that the main areas of dissatisfaction are the lack of caregiver involvement (particularly around the time of discharge), lack of person-centeredness, poor recognition of

dementia and insufficient assistance in ensuring adequate nutrition [7, 21, 34, 35, 36]. With caregiver dissatisfaction in areas of basic care [33] and nursing staff reporting feeling that optimum care is sometimes not feasible for this patient group [34, 41] it is understandable that family caregivers feel more satisfied when they themselves are involved in the care of the patient [42]. Jurgens [21] identified high caregiver expectations, which can be unrealistic, unexplored by staff, and thus difficult to meet, leading to 'hypervigilant monitoring' where caregivers seek out evidence of poor care, with the expectation that it will be found. Sons and daughters were more dissatisfied than spouses, which may be due to a cohort effect on expectations, less frequent visiting, or competing responsibilities [43,44].

Our findings are surprising in that they show that the majority of confused older patients' caregivers were mostly or very satisfied with care, regardless of setting. This study has, however, identified the characteristics of the patients, caregivers and areas of care where there is dissatisfaction. This could allow hospital staff to adopt a more focused approach to delivering high quality care by identifying those patients where it is likely to be (or be perceived as) unsatisfactory and focusing on greater involvement and communication.

The only (proxy) measure we had for care quality was the care provided on the specialist MMHU, which demonstrates that dissatisfaction was not intractable, and that specialist units provide a means of improving care. Even on the MMHU a proportion of family caregivers remained dissatisfied. This may be because delivery of consistent high quality of care can be difficult when wards have little control over the case mix of patients and when staffing levels can fluctuate due to sickness and unfilled vacancies. Jurgens also suggested that unmet expectations combined with stress and physical tiredness contributed to dissatisfaction, and that family members require specific support from staff [21]. This can be difficult to provide

on busy hospital wards, within constraints of staffing, and competing demands on staff time, in a setting designed for the delivery of acute medical care [45]. It is possible that most areas of dissatisfaction relate to the quality of communication with the caregiver. Improving communication will be a challenge. Length of stay is typically short, so there is little time to build relationships. Nursing shift patterns and a large multi-disciplinary team mean that many different staff will care for the patient. Some staff may not be in a position to keep caregivers informed, but caregivers may expect that all hospital staff they meet on the patient's ward should know about the care and plans for their relative. This should be anticipated and planned for. Some relatively simple interventions could include use of personal profile ('All about me') documents to provide background information, care diaries, early family meetings to discuss problems, expectations and progress, and routine engagement of caregivers as care partners. The prevalence of dementia in healthcare facilities implies the need to upskill all clinical staff in all adult-care specialties, and to make all ward environments appropriate for people with cognitive impairment, as it is unlikely there will be sufficient specialist beds to accommodate them all.

Future research is needed to systematically study caregiver expectations and needs, investigating methods of improving communication and engagement within resource constraints, how to support caregivers, and understanding residual patient distress and ways to relieve it.

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Conflict of Interest Disclosures:

Elements of Financial/Personal Conflicts	*A Ka Whi	uthor 1 athy H ittamore	Au Sa Go	ithor 2 Irah E Idberg	Aut Lu Bra	thor 3 Icy E dshaw	Au Ro Ha	ithor 4 wan H irwood
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Employment or Affiliation		Х		Х		Х		Х
Grants/Funds		х		Х		Х		Х
Honoraria		х		Х		Х		Х
Speaker Forum		Х		Х		Х		Х
Consultant		Х		Х		Х		Х
Stocks		Х		Х		Х		Х
Royalties		Х		Х		Х		Х
Expert Testimony		х		Х		Х		Х
Board Member		Х		Х		Х		Х

Patents	Х	Х	Х	Х
Personal Relationship	Х	Х	Х	Х

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For "yes" x mark(s): give brief explanation below:

Author Contributions:

KW acquired analyzed and interpreted data, searched literature, drafted paper

SG acquired, analyzed and interpreted data, searched literature, revised paper

LB designed and supervised analyses, and revised paper

RH conceived analyses, interpreted data, searched literature, revised paper.

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GRAPHICS

Table 1: Patient and Caregiver Characteristics Associated with Ward Allocation and Satisfaction

Questionnaire Completion

		MMHU	Geriatric	General	Satisfaction
			medical	internal	questionnaire
			ward	medical	not completed
				ward	(n=138)
Completion of caregiver		234 (75%)	156 (76%)	72 (84%)	0
satisfaction					
questionnaire					
Sex of patient	Female	129 (55%)	84 (54%)	29 (40%)	70 (51%)
Age of patient *	Median years	85 (81, 88)	85 (81, 89)	85 (80 <i>,</i> 89)	83 (77, 88)
	(IQR)				
Patient mental capacity to		56 (24%)	22 (14%)	14 (19%)	46 (33%)
consent *					
Patient residence	Alone	86 (37%)	69 (45%)	33 (46%)	64 (46%)
	Care home	66 (28%)	30 (19%)	13 (18%)	39 (28%)
	With spouse	82 (35%)	56 (36%)	26 (36%)	35 (25%)
	or relative				
Patient married/living with		77 (33%)	47 (30%)	25 (35%)	30 (23%)
partner *					
Patient cognition on	Median MMSE	14 (7, 20)	12 (3, 19)	13 (7, 17)	15 (5, 22)
admission	(IQR)				
Delirium present on		128 (55%)	98 (64%)	47 (65%)	71 (53%)
admission					
Patient activities of daily	Median	9 (5, 13)	8 (4, 12)	9 (3, 13)	10 (5, 15)
living on admission	Barthel				
	Index (IQR)				
>2 point deterioration in		152 (66%)	111 (72%)	54 (77%)	87 (67%)
Barthel Index from prior					
to acute illness					
Neuropsychiatric Inventory		217 (93%)	150 (96%)	64 (89%)	52 (38%)
(NPI) completed *					

Behavioural and	Median NPI	26 (13, 42)	25 (13, 39)	31 (19, 48)	25 (15, 38)
psychological symptoms	score (IQR)				
Caregiver relationship to	Spouse or	39 (18%)	33 (22%)	18 (28%)	6 (12%)
patient *	partner				
	Son/daughter	128 (59%)	89 (59%)	36 (56%)	23 (45%)
	Other	51 (23%)	28 (19%)	10 (16%)	22 (43%)
Involvement of other		85 (40%)	57 (38%)	27 (44%)	13 (37%)
unpaid caregivers					
High caregiver strain at	Carer Strain	100 (49%)	66 (47%)	28 (47%)	17 (52%)
admission	Index ≥7				
Caregiver psychological	0-12	86 (41%)	61 (42%)	31 (50%)	12 (36%)
wellbeing on admission	13-24	105 (50%)	67 (46%)	22 (35%)	19 (58%)
(GHQ-12)	25-36	21 (10%)	17 (12%)	9 (15%)	2 (6%)
Patient residence 90 days	Community	105 (45%)	66 (42%)	37 (51%)	63 (46%)
after admission.	Previous care	35 (15%)	20 (13%)	7 (10%)	23 (17%)
	home				
	New care	43 (18%)	29 (19%)	12 (17%)	20 (15%)
	home				
	Dead	51 (22%)	41 (26%)	16 (22%)	31 (23%)
Length of index hospital	Median days	12 (5, 23)	13 (7, 21)	9 (3, 22)	9 (5, 19)
stay	(IQR)				

Footnote: IQR Interquartile range; MMHU medical and mental health unit; MMSE Mini Mental State Examination (range 0-30, higher score indicates better cognition); Barthel Index (range 0-20, higher score indicates better functional ability); NPI Neuropsychiatric Inventory (range 0-144, higher score indicates greater number, frequency or severity of behavioural and psychiatric symptoms); Carer strain Index (range 0-13, higher score indicates greater carer strain); GHQ-12 General Health Questionnaire 12-item version (range 0-36, higher score indicates poorer psychological wellbeing).

* denotes statistically significant difference between those completing and not completing the questionnaire at P<0.05 using Chi-squared or Mann-Whitney tests

	Satisfied with overall	Dissatisfied with	Total*
	care	overall care	
	n= 403 (87%)	n=59 (13%)	
Dissatisfaction with feeding and	50/391 (13%)	33⁄58 (57%)	83⁄449 (18%)
nutrition			
Dissatisfaction with management of	66/402 (16%)	46/59 (78%)	112/461 (24%)
medical issues			
Dissatisfaction with being kept	110/400 (28%)	48/59 (81%)	158/459 (34%)
informed			
Dissatisfaction with respect	14⁄402 (3%)	30/58 (52%)	44⁄460 (10%)
Dissatisfaction with caring for confused	59/398 (15%)	42/59 (71%)	101/457 (22%)
patients			
Dissatisfaction with discharge	78/358 (22%)	44/56 (79%)	122/414 (29%)
arrangements			
Any dissatisfaction	193⁄403 (48%)	56/59 (95%)	249/462 (54%)
Very dissatisfied on any item	81/403 (20%)	51/59 (86%)	132/462(29%)

Table 2: Differences in Specific Care Domains between Caregivers who were Satisfied andDissatisfied with Overall Care.

All comparisons are p<0.001 using a Z-test

* The denominator in this column shows number of caregivers completing each question.

		Satisfied	Not	Odds Ratio	P-value
		(n=403)	satisfied	(95% CI)	
			(n=59)		
Sex	Male	193 (88%)	27 (12%)	0.91 (0.53-1.59)	0.76
	Female	210 (87%)	32 (13%)	1	
Age group (years)	65-80	92 (88%)	12 (12%)	1	0.46
	81-85	114 (83%)	24 (17%)	1.61 (0.77-3.40)	(trend)
	86-90	115 (90%)	13 (10%)	0.87 (0.38-1.99)	
	>90	82 (89%)	10 (11%)	0.93 (0.38-2.28)	
Patient residence	Alone	155 (82%)	33 (18%)	1.97 (1.04-3.73)	0.04
	Care home	99 (91%)	10 (9%)	0.93 (0.41-2.14)	0.87
	With another	148 (90%)	16 (10%)	1	
Patient cognition on	>20	99 (93%)	8 (7%)	0.56 (0.24-1.33)	0.33
admission	10-19	157 (84%)	31 (16%)	1.37 (0.74-2.54)	(trend)
(MMSE)	<10	132 (87%)	19 (13%)	1	
Delirium present on	Yes	231 (85%)	42 (15%)	1.83 (1.01-3.32)	0.05
admission	No	171 (91%)	17 (9%)	1	
Patient behavioural	0-13	103 (94%)	7 (6%)	1	0.002
and psychological	14-26	97 (89%)	12 (11%)	1.82 (0.69-4.81)	(trend)
symptoms on	27-42	90 (86%)	15 (14%)	2.45 (0.96-6.28)	
admission (NPI)	43-144	85 (79%)	22 (21%)	3.81 (1.55-9.35)	
Patient activities of	0-5	127 (89%)	15 (11%)	1	0.08
daily living at	6-10	135 (89%)	17 (11%)	1.07 (0.51-2.22)	(trend)
admission	11-15	98 (86%)	16 (14%)	1.38 (0.65-2.93)	

Table 3: Patient and Caregiver Characteristics Associated wit	h Caregiver Dissatisfaction with Over	all
Care.		

(Barthel Index)	16-20	43 (80%)	11 (20%)	2.17 (0.92-5.07)	
Deterioration in	≥2	123 (88%)	16 (12%)	1	0.67
Barthel Index	<2	276 (87%)	41 (13%)	1.14 (0.62-2.11)	
prior to					
admission					
Carer Strain Index	≥7	160 (82%)	34 (18%)	1.84 (1.03-3.26)	0.04
	<7	119 (90%)	22 (10%)	1	
Caregiver	0-12	162 (91%)	16 (9%)	1	0.002
psychological	13-24	167 (86%)	27 (14%)	1.64 (0.85-3.15)	(trend)
wellbeing at	25-36	34 (72%)	13 (28%)	3.87 (1.71-8.79)	
admission (GHQ-					
12)					
Caregiver	Spouse	83 (92%)	7 (8%)	1	
relationship to	Son/daughter	209 (83%)	44 (17%)	2.50 (1.08-5.77)	0.03
patient	Other	84 (94%)	5 (6%)	0.71 (0.22-2.31)	0.57
Involvement of	Yes	143 (85%)	26 (15%)	1.37 (0.78-2.41)	0.28
other unpaid	No	226 (88%)	30 (12%)	1	
caregivers					
Length of stay (days)	0-5	100 (85%)	17 (15%)	1	
	6-10	87 (86%)	14 (14%)	0.95 (0.44-2.03)	
	11-22	117 (89%)	15 (11%)	0.75 (0.36-1.59)	0.42
	23+	99 (88%)	13 (12%)	0.77 (0.36-1.59)	(trend)
Ward type	MMHU	214 (91%)	20 (9%)	1	
	Geriatric medical	131 (84%)	25 (16%)	2.04 (1.09-3.82)	0.03
	General medical	58 (81%)	14 (19%)	2.58 (1.23-5.42)	0.01

Footnote: CI Confidence Interval; MMSE Mini Mental State Examination (range 0-30; higher score indicates better cognition); NPI Neuropsychiatric Inventory (range 0-144, higher score indicates a greater number, frequency or severity of behavioural and psychiatric symptoms); Barthel Index (range 0-20; a higher score indicates better functional ability); Carer Strain Index (range 0-13 higher score indicates greater carer strain); GHQ-12 General Health Questionnaire 12-item version (range 0-36, higher score indicates poorer psychological wellbeing); MMHU Medical and Mental Health Unit. 'Trend' refers to a test for trend.

Table 4: Multivariate Analysis of Patient and Caregiver Admission Variables Associated with

Caregiver Dissatisfaction with Overall Care

Admission variable		Multivariate	P value	Multivariate OR	P-value
		odds ratio		(95% CI), including	
		(95% Cl) (n=418)		ward type (n=418)	
Patient Residence	Alone	2.0 (0.9-4.5)	0.09	1.8 (0.8-4.1)	0.15
	Care home	1.2 (0.5-3.3)	0.70	1.3 (0.5-3.6)	0.60
	With another	1		1	
Patient behavioural	0-13	1	0.02	1	0.03
and	14-26	1.5 (0.5-4.1)	(trend)	1.4 (0.5-3.8)	(trend)
psychological	27-42	2.2 (0.8-5.9)		2.0 (0.7-5.5)	
symptoms on	43-144	2.9 (1.1-7.7)		2.6 (1.0-7.0)	
admission (NPI)					
Patient activities of	0-5	1	0.31	1	0.21
daily living on	6-10	0.9 (0.4-2.1)	(trend)	1.0 (0.4-2.2)	(trend)
admission	11-15	1.0 (0.4-2.3)		1.1 (0.5-2.7)	
(Barthel Index)	16-20	1.3 (0.5-3.6)		1.6 (0.6-4.4)	
Caregiver	0-12	1	0.02	1	0.01
psychological	13-24	1.4 (0.7-2.8)	(trend)	1.6 (0.8-3.4)	(trend)
wellbeing at	25-36	2.6 (1.0-6.6)		2.8 (1.1-7.3)	
admission (GHQ-					
12)					
Caregiver	Spouse	1		1	
relationship to	Son/daughter	1.8 (0.7-4.8)	0.23	2.1 (0.8-5.7)	0.15
patient	Other	0.6 (0.2-2.4)	0.52	0.8 (0.2-3.1)	0.75

Ward type	MMHU	-	-	1	
	Geriatric medical			2.4 (1.2-4.8)	0.01
	General medical			3.0 (1.3-6.8)	0.01

Footnote: OR Odds ratio; CI confidence Interval; NPI Neuropsychiatric Inventory (range 0-144, higher score indicates greater number, frequency or severity of behavioural and psychiatric symptoms); Barthel Index (range 0-20, higher score indicates better functional ability); GHQ-12 General Health Questionnaire 12-item version (range 0-36, higher score indicates poorer psychological wellbeing); MMHU Medical and Mental Health Unit. 'Trend' refers to a test for trend.

Table 5: Patient and Caregiver Admission Variables Associated with Caregiver Dissatisfaction in AnyAspect of Care

		No	Any	Odds ratio (95%	p-value
		dissatisfaction	dissatisfaction	Confidence	
		(n=210)	(n=252)	Interval)	
Age group (years)	65-80	47 (45%)	57 (55%)	1	0.76
	81-85	62 (45%)	76 (55%)	1.01 (0.61-1.69)	(trend)
	86-90	57 (45%)	71 (55%)	1.03 (0.61-1.72)	
	>90	44 (48%)	48 (52%)	0.90 (0.51-1.58)	
Patient residence	Alone	72 (38%)	116 (62%)	1.65 (1.07-2.52)	0.02
	Care home	55 (50%)	54 (50 %)	1.01 (0.62-1.63)	0.98
	With another	83 (51%)	81 (49%)	1	
Patient cognition on	>20	44 (41%)	63 (59%)	1.53 (0.93-2.52)	0.08
admission	10-19	80 (43%)	108 (57%)	1.44 (0.94-2.22)	(trend)
(MMSE)	<10	78 (52%)	73 (48%)	1	
Delirium present on	Yes	137 (50%)	136 (50%)	0.63 (0.43-0.92)	0.02
admission	No	73 (39%)	115 (61%)	1	
Patient behavioural	0-13	53 (48%)	57 (52%)	1	0.3
and psychological	14-26	55 (50%)	54 (50%)	0.91 (0.54-1.55)	(trend)
symptoms (NPI)	27-42	40 (38%)	65 (62%)	1.51 (0.88-2.60)	
	43-144	48 (45%)	59 (55%)	1.14 (0.67-1.95)	
Patient admission	0-5	77 (54%)	65 (46%)	1	0.003
Barthel Index	6-10	71 (47%)	81 (53%)	1.35 (0.85-2.14)	(trend)
	11-15	43 (38%)	71 (62%)	1.96 (1.18-3.23)	
	16-20	19 (35%)	35 (65%)	2.18 (1.14-4.18)	

Deterioration in	≥2	61 (44%)	78 (56%)	1	0.67
Barthel Index	<2	146 (46%)	171 (54%)	0.92 (0.61-1.37)	
prior to					
admission					
Carer Strain Index	≥7	81 (42%)	113 (58%)	1.32 (0.89-1.95)	0.17
	<7	103 (49%)	109 (51%)	1	
Caregiver	0-12	90 (51%)	88 (49%)	1	0.05
psychological	13-24	80 (41%)	114 (59%)	1.46 (0.97-2.20)	(trend)
wellbeing at	25-36	18(38%)	29 (62%)	1.65 (0.85-3.18)	
admission (GHQ-					
12)					
Caregiver	Spouse	45 (50%)	45 (50%)	1	
relationship to	Son/daughter	104 (41%)	149 (59%)	1.43 (0.88-2.32)	0.15
patient	Other	47 (53%)	42 (47%)	0.89 (0.50-1.61)	0.71
Involvement of	Yes	82 (49%)	87 (51%)	0.81 (0.55-1.20)	0.30
other unpaid	No	111 (43%)	145 (57%)	1	
caregivers					
Length of hospital	0-5	51 (44%)	66 (56%)	1	0.34
stay (days)	5-10	42 (42%)	59 (58%)	1.09 (0.63-1.86)	(trend)
	11-22	63 (48%)	69 (52%)	0.85 (0.51-1.40)	
	23+	54 (48%)	58 (52%)	0.83 (0.49-1.40)	
Ward type	MMHU	117 (50%)	117 (50%)	1	
	Geriatric medical	69 (44%)	87 (56%)	1.26 (0.84-1.89)	0.26
	General medical	24 (33%)	48 (67%)	2.0 (1.15-3.48)	0.01

Footnote: MMSE Mini Mental State Examination (range 0-30); NPI Neuropsychiatric Inventory (range 0-144, higher score indicates greater number, frequency or severity of behavioural and psychiatric symptoms); Barthel Index (range 0-20 higher score indicates better functional ability); Carer Strain Index (range 0-13, higher score indicates greater carer strain); GHQ-12 General Health Questionnaire 12-item version (range 0-36, higher score indicates poorer psychological wellbeing); MMHU Medical and Mental Health Unit. 'Trend' refers to a test for trend.