Factors Associated with Family Caregiver Dissatisfaction with Acute Hospital Care of Older Cognitively Impaired Relatives

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OBJECTIVES: To identify patient and caregiver characteristics associated with caregiver dissatisfaction with hospital care of cognitively impaired elderly adults.

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

SETTING: An 1,800-bed general hospital in England providing the only emergency medical services in its area.

PARTICIPANTS: Cognitively impaired individuals aged 65 and older randomly assigned to a specialist unit or standard geriatric or internal medical wards (N = 600) and related caregivers (N = 488).

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: Four hundred sixty-two 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 well-being at admission, a diagnosis of delirium, and the relationship between the caregiver and the patient. There was less dissatisfaction from caregivers of patients managed on the specialist Medical and Mental Health Unit than those on 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. J Am Geriatr Soc 62:2252–2260, 2014.

Key words: aged; general hospitals; satisfaction; dementia; delirium; caregivers

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

Satisfaction is an important measure of health service performance. The U.K. National Health Service (NHS) Outcomes Framework cites “a positive patient experience of care” as one of its five domains.8 Satisfaction is mostly ascertained according to self-report, but this is often not possible for individuals 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 individuals with dementia in the 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.11 The unit was compared over 18 months in a randomized controlled trial with standard hospital care consisting of generic geriatric medical and internal medicine wards. 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, whereas 91% on MMHU were mostly or very satisfied.13

This is a report of a secondary analysis of data from the trial that aimed to identify patient and caregiver
characteristics associated with caregiver dissatisfaction to identify improvements that might better meet their needs in the future.

METHODS

Study Population and Parent Study

Individuals admitted for emergency acute medical care to a large general hospital in England, who were aged 65 and older and whom Admissions Unit physicians or nurses identified as being “confused” were recruited. “Confused” is a vague term implying cognitive impairment, but Admissions Unit staff found it acceptable and understood it; and it was simple enough to identify appropriate individuals rapidly in a busy clinical setting without delaying the admissions pathway. Almost all individuals had delirium, dementia, or both,12,13 and 93% were subsequently found to have a Mini–Mental State Examination score of 24 or less out of 30. All recruited individuals were retained in the study. MMHU staff entered potentially suitable individuals on a computerized screening log, and if a bed was available on the specialist unit, they were 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 using a web-based algorithm hosted by a clinical trials unit, and the sequence was concealed from staff who allocated patients. Standard hospital care was provided on six geriatric medical wards and five internal medical wards. Individuals with an overriding clinical need for another clinical service (e.g., critical care, stroke unit, surgery), who did not live within the local health and social care administrative areas (determined according to home address postal code), or who were unable to speak English and had no available family or other nonprofessional translator were excluded. An attempt was made to recruit a caregiver who was a family member or other informal caregiver who saw the individual 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 provide written informed consent. Agreement for participation was sought from a family member or caregiver for individuals lacking mental capacity.14 Caregivers also provided written informed consent for their own participation in the study.

Clinical researchers (nurses and psychology graduates) collected trial baseline information through interviews with participating caregivers, informants, and ward staff; examination of clinical records. Caregivers were asked to complete a questionnaire regarding their own health and caring responsibilities.

Demographic and social information and results of 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 (Neuropsychiatric Inventory17), and dependency in activities of daily living at the time of admission and before the acute illness (Barthel Index18 scored out of 20) were recorded. Caregiver strain and psychological well-being were measured using the Caregiver Strain Index19 and General Health Questionnaire.20

One to 3 weeks after the individual had been discharged from his or her index hospital admission, researchers, who were blind to ward allocation, telephoned the nominated caregiver and completed a satisfaction questionnaire. The questionnaire comprised 10 items (overall care, admission arrangements, car parking, nutrition and feeding, medical management, being kept informed, dignity and respect, meeting the needs of a confused individual, discharge arrangements, and timing of discharge) using Likert-type scales (very or mostly satisfied, mostly or very satisfied). Bereaved caregivers were approached to complete the questionnaire 6 weeks after the date of death, with items regarding timing of discharge omitted.

Secondary Statistical Analysis

A cohort analysis was conducted to compare potential explanatory variables of caregivers who did and did not express dissatisfaction with care. Participants for this analysis comprised all randomized patients and their caregivers for whom complete data were available.

Two sets of analyses were conducted. First, data were dichotomized according to whether the caregiver was satisfied (mostly or very) or dissatisfied (mostly or very) overall with the care that the patient received. Second, 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, because 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 determined using chi-square, 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 $P < .10$ were further examined using multivariate logistic regression. Caregiver strain and psychological well-being (General Health Questionnaire) were strongly correlated, as were Delirium Rating Scale score and Neuropsychiatric Inventory score, and in each case, the more strongly associated of the two variables was retained in the final model. It has previously been shown that ward type (MMHU or standard care) is associated with satisfaction,13 so this was included in the model. Where explanatory variables were in ordered categories (ordinal), including grouped numerical data, a test for trend was performed 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
“10 events per variable” rule, the current analysis had sufficient power to examine a multivariate model with five to six explanatory variables.

Ethical Approval
The Nottingham Research Ethics Committee approved the study.

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

Three hundred ten 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. Individuals 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%). Individuals on general internal medical wards were more likely to be male (60% vs 45%) and to have a spouse (28% vs 18%), and their length of hospital stay was shorter (median 9 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 (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 well-being 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 individuals 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, vs MMHU; Table 3).

Multivariate Associations with Dissatisfaction
In multivariate analyses, higher levels of behavioral and psychological symptoms (top quartile OR = 2.9, 95% CI = 1.1–7.7) and poorer caregiver psychological well-being (OR = 2.6, 95% CI = 1.0–6.6) remained strongly associated with dissatisfaction. Including ward type in the model had little effect 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, vs 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 that caregivers of individuals 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 less physical disability in patients (Barthel Index 16–20, OR = 2.18, 95% CI = 1.14–4.18; Table 5).

DISCUSSION
Fifty-four percent of caregivers of cognitively impaired older adults were dissatisfied with some aspects of hospital care, but 87% were mostly or very satisfied with care overall. More than one-third were dissatisfied with how well they were kept informed, and one-quarter were 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 MMHU 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 in which 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, protecting outcome assessment from bias. Participants comprised consecutive patients potentially suitable for the MMHU and as such were a representative sample of cognitively impaired older people admitted to a general hospital and their caregivers.

Person-centered dementia care holds that caregivers (and the institutions and systems they work in) must value people with dementia; should individualize care, taking into account 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 need); and recognize the importance of the social environment for well-being, in particular relationships with family and

Table 1. Patient and Caregiver Characteristics Associated with Ward Allocation and Satisfaction Questionnaire Completion

| Characteristic                                      | Medical and Mental Health Unit | Geriatric Medical Ward N (%) | General Internal Medical Ward | Satisfaction Questionnaire Not Completed, n = 138 |
|-----------------------------------------------------|--------------------------------|------------------------------|-------------------------------|-----------------------------------------------|
| Completion of caregiver satisfaction questionnaire  | 234 (75)                       | 156 (76)                     | 72 (84)                       | 0                                             |
| Female patient                                      | 129 (55)                       | 84 (54)                      | 29 (40)                       | 70 (51)                                       |
| Patient age, median (IQR)                           | 85 (81–88)                     | 85 (81–89)                   | 85 (80–89)                    | 83 (77–88)                                    |
| Patient mental capacity to consent                  | 56 (24)                        | 22 (14)                      | 14 (19)                       | 46 (33)                                       |
| Patient residence                                   |                                |                              |                               |                                               |
| Alone                                                | 86 (37)                        | 69 (45)                      | 33 (46)                       | 64 (46)                                       |
| Care home                                            | 66 (28)                        | 30 (19)                      | 13 (18)                       | 39 (28)                                       |
| With spouse or relative                             | 82 (35)                        | 56 (36)                      | 26 (36)                       | 35 (25)                                       |
| Patient married/living with partner                  | 77 (33)                        | 47 (30)                      | 25 (35)                       | 30 (23)                                       |
| Mini–Mental State Examination score, median (IQR)   | 14 (7–20)                      | 12 (3–19)                    | 13 (17–21)                    | 15 (5–22)                                     |
| Delirium present on admission                        | 128 (55)                       | 98 (64)                      | 47 (65)                       | 71 (53)                                       |
| Barthel Index, median (IQR)                          | 9 (5–13)                       | 8 (4–12)                     | 9 (3–13)                      | 10 (5–15)                                     |
| >2 point deterioration in Barthel Index from prior to acute illness | 152 (66)                       | 111 (72)                     | 54 (77)                       | 87 (67)                                       |
| Neuropsychiatric inventory completed                 | 217 (93)                       | 150 (96)                     | 64 (89)                       | 52 (38)                                       |
| Neuropsychiatric Inventory score, median (IQR)       | 26 (13–42)                     | 25 (13–39)                   | 31 (19–48)                    | 25 (15–38)                                    |
| Caregiver relationship to patient                   |                                |                              |                               |                                               |
| Spouse or partner                                    | 39 (18)                        | 33 (22)                      | 18 (28)                       | 6 (12)                                        |
| Son or daughter                                      | 128 (59)                       | 89 (59)                      | 30 (56)                       | 23 (45)                                       |
| Other                                                | 51 (23)                        | 28 (19)                      | 10 (16)                       | 22 (43)                                       |
| Involvement of other unpaid caregivers               | 85 (40)                        | 57 (38)                      | 27 (44)                       | 13 (37)                                       |
| Caregiver Strain Index ≥7                            | 100 (49)                       | 66 (47)                      | 28 (47)                       | 17 (52)                                       |
| Caregiver psychological well-being on admission (General Health Questionnaire 12-item version) |                                |                              |                               |                                               |
| 0–12                                                | 86 (41)                        | 61 (42)                      | 31 (50)                       | 12 (36)                                       |
| 13–24                                               | 105 (50)                       | 67 (46)                      | 22 (35)                       | 19 (58)                                       |
| 25–36                                               | 21 (10)                        | 17 (12)                      | 9 (15)                        | 2 (6)                                         |
| Patient residence 90 days after admission            |                                |                              |                               |                                               |
| Community                                            | 105 (45)                       | 66 (42)                      | 37 (51)                       | 63 (46)                                       |
| Previous care home                                   | 35 (15)                        | 20 (13)                      | 7 (10)                        | 23 (17)                                       |
| New care home                                        | 43 (18)                        | 29 (19)                      | 12 (17)                       | 20 (15)                                       |
| Dead                                                 | 51 (22)                        | 41 (26)                      | 16 (22)                       | 31 (23)                                       |
| Length of index hospital stay, days, median (IQR)    | 12 (5–23)                      | 13 (7–21)                    | 9 (3–22)                      | 9 (5–19)                                      |

IQR = interquartile range.

- Statistically significant difference between those completing and not completing the questionnaire at P < .05 using chi-square or Mann–Whitney test.
- Range 0–20; higher score indicates better functional ability.
- Range 0–144; higher score indicates greater number, frequency, or severity of behavioral and psychiatric symptoms.
- Range 0–13; higher score indicates greater caregiver strain.
- Range 0–36; higher score indicates poorer psychological well-being.

Table 2. Dissatisfaction with Specific Care Domains According to Satisfaction with Overall Care

| Care Domain                                | Satisfied with Overall Care, n = 403 (87%) | Dissatisfied with Overall Care, n = 59 (13%) | Total |
|--------------------------------------------|--------------------------------------------|------------------------------------------------|-------|
|                                            | n/N (% )                                   | n/N (%)                                        |       |
| Dissatisfaction with feeding and nutrition  | 50/391 (13)                                | 33/58 (57)                                     | 83/449 (18) |
| Dissatisfaction with management of medical concerns | 66/402 (16)                                | 46/59 (78)                                     | 112/461 (24) |
| Dissatisfaction with being kept informed    | 110/400 (28)                               | 48/59 (81)                                     | 158/459 (34) |
| Dissatisfaction with respect                | 14/402 (3)                                 | 30/58 (52)                                     | 44/460 (10) |
| Dissatisfaction with caring for confused patients | 59/388 (15)                               | 42/59 (71)                                     | 101/457 (22) |
| Dissatisfaction with discharge arrangements  | 78/356 (22)                                | 44/56 (79)                                     | 122/414 (29) |
| 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) |

All comparisons are P < .001 using a Z-test.

Denominator shows number of caregivers completing each question.
Table 3. Patient and Caregiver Characteristics Associated with Caregiver Dissatisfaction with Overall Care

| Characteristic                                      | Satisfied, n = 403 | Not Satisfied, n = 59 N (%) | Odds Ratio (95% Confidence Interval) | P-Value |
|-----------------------------------------------------|--------------------|-----------------------------|--------------------------------------|---------|
| Sex                                                 |                    |                             |                                      |         |
| Male                                                | 193 (88)           | 27 (12)                     | 0.91 (0.53–1.59)                     | .76     |
| Female                                              | 210 (87)           | 32 (13)                     | 1                                    |         |
| Age                                                 |                    |                             |                                      |         |
| 65–80                                               | 92 (88)            | 12 (12)                     | 1                                    | .46 (trend) |
| 81–85                                               | 114 (83)           | 24 (17)                     | 1.61 (0.77–3.40)                     |         |
| 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)                     | .04     |
| Care home                                           | 99 (91)            | 10 (9)                      | 0.93 (0.41–2.14)                     | .87     |
| With another                                        | 148 (90)           | 16 (10)                     | 1                                    |         |
| Mini-Mental State Examination score                 |                    |                             |                                      |         |
| >20                                                 | 99 (93)            | 8 (7)                       | 0.56 (0.24–1.33)                     | .33 (trend) |
| 10–19                                               | 157 (84)           | 31 (16)                     | 1.37 (0.74–2.54)                     |         |
| <10                                                 | 132 (87)           | 19 (13)                     | 1                                    |         |
| Delirium present on admission                       |                    |                             |                                      |         |
| Yes                                                 | 231 (85)           | 42 (15)                     | 1.83 (1.01–3.32)                     | .05     |
| No                                                  | 171 (91)           | 17 (9)                      | 1                                    |         |
| Neuropsychiatric Inventory at admissiona             |                    |                             |                                      |         |
| 0–13                                                | 103 (94)           | 7 (6)                       | 1                                    | .002 (trend) |
| 14–26                                               | 97 (89)            | 12 (11)                     | 1.82 (0.69–4.81)                     |         |
| 27–42                                               | 90 (86)            | 15 (14)                     | 2.45 (0.96–6.28)                     |         |
| 43–144                                              | 85 (79)            | 22 (21)                     | 3.81 (1.55–9.35)                     |         |
| Barthel Index at admissionb                         |                    |                             |                                      |         |
| 0–5                                                 | 127 (89)           | 15 (11)                     | 1                                    | .08 (trend) |
| 6–10                                                | 135 (89)           | 17 (11)                     | 1.07 (0.51–2.22)                     |         |
| 11–15                                               | 98 (86)            | 16 (14)                     | 1.38 (0.65–2.93)                     |         |
| 16–20                                               | 43 (80)            | 11 (20)                     | 2.17 (0.92–5.07)                     |         |
| Deterioration in Barthel Index before admission     |                    |                             |                                      |         |
| ≥2                                                  | 123 (88)           | 16 (12)                     | 1                                    | .67     |
| <2                                                  | 276 (87)           | 41 (13)                     | 1.14 (0.62–2.11)                     |         |
| Carer Strain Indexc                                 |                    |                             |                                      |         |
| ≥7                                                  | 160 (82)           | 34 (18)                     | 1.84 (1.03–3.26)                     | .04     |
| <7                                                  | 119 (90)           | 22 (10)                     | 1                                    |         |
| Caregiver psychological well-being at admission (General Health Questionnaire 12-item version)d | | | | |
| 0–12                                                | 162 (91)           | 16 (9)                      | 1                                    | .002 (trend) |
| 13–24                                               | 167 (86)           | 27 (14)                     | 1.64 (0.85–3.15)                     |         |
| 25–36                                               | 34 (72)            | 13 (28)                     | 3.87 (1.71–8.79)                     |         |
| Caregiver relationship to patient                   |                    |                             |                                      |         |
| Spouse                                              | 83 (92)            | 7 (8)                       | 1                                    |         |
| Son/daughter                                        | 209 (83)           | 44 (17)                     | 2.50 (1.08–5.77)                     | .03     |
| Other                                               | 84 (94)            | 5 (6)                       | 0.71 (0.22–2.31)                     | .57     |
| Involvement of other unpaid caregivers               |                    |                             |                                      |         |
| Yes                                                 | 143 (85)           | 26 (15)                     | 1.37 (0.78–2.41)                     | .28     |
| No                                                  | 226 (88)           | 30 (12)                     | 1                                    |         |
| Length of stay (days)                               |                    |                             |                                      |         |
| 0–5                                                 | 100 (85)           | 17 (15)                     | 1                                    | .42 (trend) |
| 6–10                                                | 87 (86)            | 14 (14)                     | 0.95 (0.44–2.03)                     |         |
| 11–22                                               | 117 (89)           | 15 (11)                     | 0.75 (0.36–1.59)                     |         |
| ≥23                                                 | 99 (88)            | 13 (12)                     | 0.77 (0.36–1.59)                     |         |
| Ward type                                           |                    |                             |                                      |         |
| Medical and Mental Health Unit                      | 214 (91)           | 20 (9)                      | 1                                    |         |
| Geriatric medical                                   | 131 (84)           | 25 (16)                     | 2.04 (1.09–3.82)                     | .03     |
| General medical                                     | 58 (81)            | 14 (19)                     | 2.58 (1.23–5.42)                     | .01     |

a Range 0–144; higher score indicates a greater number, frequency, or severity of behavioral and psychiatric symptoms.
b Range 0–20; higher score indicates better functional ability.
c Range 0–13; higher score indicates greater caregiver strain.
d Range 0–36; higher score indicates poorer psychological well-being.
Table 4. Multivariate Analysis of Patient and Caregiver Admission Variables Associated with Caregiver Dissatisfaction with Overall Care (N = 418)

| Admission Variable                              | Multivariate OR (95% CI) | P-Value | Multivariate OR (95% CI), Including Ward Type | P-Value |
|-------------------------------------------------|--------------------------|---------|-----------------------------------------------|---------|
| Patient residence (reference with another)      |                          |         |                                               |         |
| Alone                                           | 2.0 (0.9–4.5)            | .09     | 1.8 (0.8–4.1)                                 | .15     |
| Care home                                        | 1.2 (0.5–3.3)            | .70     | 1.3 (0.5–3.6)                                 | .60     |
| Barthel Index at admission (reference 0–5)      |                          |         |                                               |         |
| 6–10                                            | 0.9 (0.4–2.1)            | .31     | 1.0 (0.4–2.2)                                 | .21     |
| 11–15                                           | 1.0 (0.4–2.3)            | .75     | 1.1 (0.5–2.7)                                 |         |
| 16–20                                           | 1.3 (0.5–3.6)            | .60     | 1.6 (0.6–4.4)                                 |         |
| Caregiver psychological well-being at admission |                          |         |                                               |         |
| (General Health Questionnaire 12-item version;   |                          |         |                                               |         |
| reference 0–12)                                  |                          |         |                                               |         |
| 13–24                                           | 1.4 (0.7–2.8)            | .02     | 1.6 (0.8–3.4)                                 | .01     |
| 25–36                                           | 2.6 (1.0–6.6)            | .15     | 2.8 (1.1–7.3)                                 |         |
| Caregiver relationship to patient (reference     |                          |         |                                               |         |
| spouse)                                         |                          |         |                                               |         |
| Son or daughter                                 | 1.8 (0.7–4.8)            | .23     | 2.1 (0.8–5.7)                                 | .15     |
| Other                                           | 0.6 (0.2–2.4)            | .52     | 0.8 (0.2–3.1)                                 | .75     |
| Ward type (reference Medical and Mental Health   |                          |         |                                               |         |
| Unit)                                           |                          |         |                                               |         |
| Geriatric medical                               | 2.4 (1.2–4.8)            | .01     |                                               |         |
| General medical                                 | 3.0 (1.3–6.8)            | .01     |                                               |         |

OR = odds ratio; CI = confidence interval.

Range 0–144; higher score indicates a greater number, frequency, or severity of behavioral and psychiatric symptoms. Range 0–20; higher score indicates better functional ability. Range 0–36; higher score indicates poorer psychological well-being.

professional caregivers. MMHU staff were trained in this philosophy, and ward medical and nursing leaders encouraged and modeled such behaviors. Specialist mental health nursing and therapy staff were employed to work alongside regular ward staff. A program 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 toward family caregivers was adopted.11 Satisfaction on MMHU was greater than on generic geriatric medical wards, where care was based on comprehensive geriatric assessment and whose staff had general experience in the management of delirium and dementia.

This study had limitations. Family caregivers are usually present for only 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 the knowledge that the patient was cared for on a specialist ward may have biased opinions. Expectations, news reports, and previous experiences in the hospital may have influenced their experiences.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 of ward types, there is little reason to believe that questions would have been interpreted differently on different ward types or that desirability biases would have been different. Despite the study size, some of the analyses in the current study lacked precision, indicated by wide 95% confidence intervals on effect sizes, because the sample size was determined for the primary outcome measure of the main trial.13 No data were available 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 were available on the MMHU. On request, mental health nursing and medical staff would occasionally assess individuals 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 in different wards to cover shortages elsewhere during out-of-hours work, because they were rotating between services (e.g., junior doctors), or because they were 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 Kingdom23 and the United States,24 large surveys are conducted with all patients discharged from the hospital to assess satisfaction with a variety of outcomes, including communication with health professionals, medications, pain control, and discharge planning. In general, most people are satisfied with health care. Individuals with dementia may be included in these surveys, but there are no questions to identify them,
and in many (or most) cases, they do not participate because of memory and other impairments. There has been little previous systematic study of caregivers’ experiences of general hospital care for people with cognitive impairment, but one study concluded that there could be a disparity between caregiver and staff member ideas of what constitutes quality care, with lack of information sharing identified as an important factor in caregiver

| Variable                                      | No Dissatisfaction, n = 210 N (%) | Any Dissatisfaction, n = 252 | Odds Ratio (95% Confidence Interval) | P-Value |
|------------------------------------------------|-----------------------------------|------------------------------|-------------------------------------|---------|
| **Age**                                        |                                   |                              |                                     |         |
| 65–80                                          | 47 (45)                           | 57 (55)                      | 1                                   | .76 (trend) |
| 81–85                                          | 62 (45)                           | 76 (55)                      | 1.01 (0.61–1.69)                    |         |
| 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)                    | .02     |
| Care home                                      | 55 (50)                           | 54 (50)                      | 1.01 (0.62–1.63)                    | .98     |
| With another                                   | 83 (51)                           | 81 (49)                      | 1                                   |         |
| **Mini-Mental State Examination score on admission** |                                   |                              |                                     |         |
| >20                                            | 44 (41)                           | 63 (59)                      | 1.53 (0.93–2.52)                    | .08 (trend) |
| 10–19                                         | 80 (43)                           | 108 (57)                     | 1.44 (0.94–2.22)                    |         |
| <10                                           | 78 (52)                           | 73 (48)                      | 1                                   |         |
| **Delirium present on admission**              |                                   |                              |                                     |         |
| Yes                                            | 137 (50)                          | 136 (50)                     | 0.63 (0.43–0.92)                    | .02     |
| No                                             | 73 (39)                           | 115 (61)                     | 1                                   |         |
| **Admission Neuropsychiatric Inventory**       |                                   |                              |                                     |         |
| (reference 0–13)                               |                                   |                              |                                     |         |
| 0–13                                          | 53 (48)                           | 57 (52)                      | 1                                   | .30 (trend) |
| 14–26                                         | 55 (50)                           | 54 (50)                      | 0.91 (0.54–1.55)                    |         |
| 27–42                                         | 40 (38)                           | 65 (62)                      | 1.51 (0.88–2.60)                    |         |
| 43–144                                        | 46 (45)                           | 59 (55)                      | 1.14 (0.67–1.95)                    |         |
| **Admission Barthel Index**                    |                                   |                              |                                     |         |
| 0–5                                           | 77 (54)                           | 65 (46)                      | 1                                   | .003 (trend) |
| 6–10                                          | 71 (47)                           | 81 (53)                      | 1.35 (0.85–2.14)                    |         |
| 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 Barthel Index before admission** |                                   |                              |                                     |         |
| ≥2                                            | 61 (44)                           | 78 (56)                      | 1                                   | .67     |
| <2                                            | 146 (46)                          | 171 (54)                     | 0.92 (0.61–1.37)                    |         |
| **Carer Strain Index**                        |                                   |                              |                                     |         |
| ≥7                                            | 81 (42)                           | 113 (58)                     | 1.32 (0.89–1.95)                    | .17     |
| <7                                            | 103 (49)                          | 109 (51)                     | 1                                   |         |
| **Caregiver psychological well-being at admission (General Health Questionnaire 12-item version)** |                                   |                              |                                     |         |
| 0–12                                          | 90 (51)                           | 88 (49)                      | 1                                   | .05 (trend) |
| 13–24                                         | 80 (41)                           | 114 (59)                     | 1.46 (0.97–2.20)                    |         |
| 25–36                                         | 18 (38)                           | 29 (62)                      | 1.65 (0.85–3.18)                    |         |
| **Caregiver relationship to patient**          |                                   |                              |                                     |         |
| Spouse                                        | 45 (50)                           | 45 (50)                      | 1                                   |         |
| Son or daughter                               | 104 (41)                          | 149 (59)                     | 1.43 (0.88–2.32)                    | .15     |
| Other                                         | 47 (53)                           | 42 (47)                      | 0.89 (0.50–1.61)                    | .71     |
| **Involvement of other unpaid caregivers**     |                                   |                              |                                     |         |
| Yes                                           | 82 (49)                           | 87 (51)                      | 0.81 (0.55–1.20)                    | .30     |
| No                                            | 111 (43)                          | 145 (57)                     | 1                                   |         |
| **Length of hospital stay (days)**             |                                   |                              |                                     |         |
| 0–5                                           | 51 (44)                           | 66 (56)                      | 1                                   | .34 (trend) |
| 5–10                                          | 42 (42)                           | 59 (58)                      | 1.09 (0.63–1.86)                    |         |
| 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**                                 |                                   |                              |                                     |         |
| Medical and Mental Health Unit                 | 117 (50)                          | 117 (50)                     | 1                                   |         |
| Geriatric medical                             | 69 (44)                           | 87 (56)                      | 1.26 (0.84–1.89)                    | .26     |
| General medical                               | 24 (33)                           | 48 (67)                      | 2.0 (1.15–3.48)                     | .01     |

a Range 0–144; higher score indicates greater number, frequency, or severity of behavioral and psychiatric symptoms.
b Range 0–20; higher score indicates better functional ability.
c Range 0–13; higher score indicates greater caregiver strain.
d Range 0–36; higher score indicates poorer psychological well-being.
dissatisfaction.26 Studies that have considered hospitalization and the needs of relatives more generally have 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 care30 and the ability and suitability of individual members of staff31 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.7,21,32–36 Behavioral disturbance in patients has long been associated with poor psychological health in caregivers.37–40 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.4,40 There is evidence indicating that many aspects of hospital care for individuals 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.7,21,34–36 With caregiver dissatisfaction in areas of basic care33 and nursing staff reporting feeling that optimum care is sometimes not feasible for this group,34,43 it is understandable that family caregivers feel more satisfied when they themselves are involved in the care of the patient.42 High caregiver expectations can be unrealistic and unexplored by staff and thus difficult to meet, leading to “hypervigilant monitoring,” with caregivers seeking out evidence of poor care, with the expectation that it will be found.21 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

The findings of the current study are surprising in that they show that the majority of caregivers of confused older adults were mostly or very satisfied with care, regardless of setting, although this study 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 cases in which care is likely to be perceived as unsatisfactory and focusing on greater involvement and communication.

Even on the MMHU, a proportion of family caregivers were dissatisfied. This may be because delivery of consistent high-quality care can be difficult when wards have little control over case mix and staffing levels. It has been suggested that unmet expectations combined with stress and physical tiredness contribute 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 multidisciplinary team mean that many different staff will care for the individual. Some staff may not be in a position to keep caregivers informed, but caregivers may expect that all hospital staff they meet on the ward should know about the care of and plans for their relative. This should be anticipated and planned for. Some simple interventions could include use of personal profile documents (All About Me)46 to provide background information and 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 adult-care specialties and to make all ward environments appropriate for people with cognitive impairment, because it is unlikely that there will be sufficient specialist beds to accommodate them all.

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

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