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Anxiety in family caregivers of hospitalized persons with dementia: Contributing factors and responses

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Abstract

Background—Baseline health and functional vulnerabilities increase the risk for complications in persons with dementia and predispose family caregivers (FCGs) to increased stress.

Methods—This secondary analysis used a combined quantitative and qualitative approach. Regression analyses examined the contribution of patient and family caregiver characteristics to FCG anxiety. Interviews with FCGs explored the experiences and responses of FCGs during hospitalization of their family member with dementia.

Results—Lower patient physical function and higher caregiver strain were associated with higher FCG anxiety. FCGs described the following themes related to the hospitalization: 1) added strain; 2) care-related worries; 3) keeping vigil; 4) need to be heard; and 5) enablers of family caregivers.

Conclusions—Routine evaluation of caregiver strain and baseline patient function is integral to informing the transitional planning for persons with dementia. The FCG responses suggest that a multi-factorial approach (family-centered policies of partnership in care, staff education addressing the specialized needs of patients and family- members, and attention to promoting

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Conflicts of Interest

For the remaining authors none were declared.

functional recovery) may benefit both hospitalized patients with dementia as well as FCGs and warrants future research.

Keywords

acute care; dementia; family caregiver; mixed methods; function

Approximately 75% of the estimated 5.4 million persons living with Alzheimer's disease and other dementias (collectively referred to as AD) in the United States are cared for by family caregivers (FCGs).¹ They are estimated to provide 17 billion hours of care annually for a total cost valued at over \$200 billion.² The demands of caregiving, whether it is provided in the form of care provision (hands on care) or care management (arranging for care and services),³ take its toll. Persons with dementia generally require high levels of care, so FCGs support often comes at a cost of increased caregiver stress and morbidity, and poorer quality of life.⁴⁻⁷ A systematic review that examined the presence of anxiety in caregivers of persons with dementia found that approximately a quarter of caregivers of community-residing people with dementia experienced clinically significant anxiety, found to be more common than in matched controls.⁵ Factors associated with psychological morbidity (e.g., strain, anxiety, depression) on dementia family caregivers include being female, being a spousal caregiver, additional stressful life events, poor physical health, decreased quality of relationship between caregiver/care receiver, and the presence of behavioral and psychological symptoms in the person with dementia.^{5,7, 8}

The Experience and Outcomes of Hospitalization

The likelihood is high that the person with dementia will be hospitalized during their course of illness. Individuals with AD have more than three times as many hospital stays per year as other older people.¹ Approximately 3.2 million persons with dementia enter the hospital each year often presenting new and/or exacerbated problems for both the patient and the FCG.¹ Although hospitalization may offer respite for some FCGs, the stress of caregiving typically persists and in fact often intensifies, exacerbated by the anxiety associated with the acute illness and hospital stay.^{9,10} Family caregivers often describe a sense of powerlessness about their ability to positively impact their loved ones' recovery,¹¹ and consequently experience worry and associated anxiety, as well as depression.^{12, 13} Additionally, as compared to other FCGs, caregivers of persons with dementia bring higher caregiver strain to the hospital experience, challenging their coping abilities.¹⁴ These baseline vulnerabilities may impact their sense of well-being and influence their ability to fulfill their caregiving role during the hospitalization and post-acute care of the person with dementia.

When hospitalized, persons with dementia are more likely to experience complications including functional decline, delirium, and nutritional problems than those older individuals who are cognitively intact.¹⁵⁻¹⁷ Due to illness or the stress of hospitalization, the person with dementia may have an exacerbation of behavior symptoms due to delirium, inability to express his or her concerns, and/or physical symptoms.¹⁸ These behaviors may be managed with psychotropic medication^{19, 20} increasing the risk for oversedation, dysphagia, and increased mortality.²⁰ Persons with dementia also have longer hospital stays,²¹ are more likely to experience protracted delirium²² failure to return to baseline physical and

cognitive function²³ higher rates of hospital readmission,²³ transitions to long-term nursing home stays, and mortality.^{21–23}

Poor outcomes in hospitalized persons with dementia are related in part to inadequate assessment of baseline status and lack of attention to preserving cognitive and physical abilities, despite a growing awareness of the urgent need to attend to these issues.^{22,24} FCGs can mitigate these problems by providing a physical presence and advocating for the patient's care preferences.^{10,11} They can also provide vital information regarding the health, baseline cognition, prior level of function, activity profile, interests, and response to treatment of the person with dementia.^{9, 10} FCGs also directly provide and/or guide staff efforts to prevent delirium, functional decline and other complications through cognitive stimulation and emotional support, assistance with meals, and engagement in physical activity.^{9, 25} In order to effectively partner with FCGs to improve hospital outcomes for the person with dementia, it is important to understand the FCGs' source of vulnerabilities as well as their perspective of the hospitalization.

Very little research has examined the experience of FCG during periods of acute illness of the person with dementia. An understanding of the FCG response to hospitalization will facilitate family-centered interventions that support the well-being and effectiveness of FCGs, and in turn promote better patient outcomes. The purpose of this study was to examine the contributing factors to anxiety in FCGs of hospitalized persons with dementia and explore FCGs' perspectives of the acute illness and hospitalization.

METHODS

This descriptive, secondary analysis used a combined quantitative and qualitative approach using baseline data from a study that examined the effectiveness of a system-level intervention designed to improve post-acute functional outcomes in hospitalized persons with dementia.⁹

Setting/Sample

Fifty dyads of patients and their family member were recruited from three medical units of a suburban hospital in the Northeast US. Patients aged 65 or older who were able to understand and speak English, were not receiving hospice care, did not have a condition with a life expectancy < 6 months, and demonstrated cognitive impairment (Modified Blessed Dementia Rating Scale > 2)²⁶ were included in the study. Family members age 21 and above whose relatives met inclusion criteria were eligible if they: a) could speak and read English; b) were related to the patient by blood, marriage, adoption, or affinity as a significant other; and c) were primary family caregivers who either lived with the patient or continued to provide caregiving from an alternate residence. The study was approved by the Institutional Review Board of the New York University School of Medicine and the study site.

Data Collection

Following informed consent of both patient and FCG, patient socio-demographic and health information was extracted from the medical record and evaluation of cognitive status and

functional status were conducted by trained data collectors within 24 hours of admission. FCGs completed a demographic survey, as well as standardized survey instruments within 48 hours of admission. Interviews with FCG were conducted by the researcher in a private area, using a semi-structured interview guide. The duration of the interviews varied between 20 and 30 minutes. All open-ended interview responses were transcribed verbatim.

Quantitative data—FCG data included demographic information on age, race, sex, education, marital status, work status, and role in the family (spouse/life partner, son, daughter, other).

The *quality of the relationship* between caregiver and patient was measured by the Mutuality Scale, a tool with established internal consistency and reliability.²⁷ The Mutuality Scale reflects the interactive nature of relationship quality, including dimensions of reciprocity, love, shared pleasurable activities, and shared values. Fifteen items are rated on a 5-point scale that ranges from 0 (not at all) to 4 (a great deal) with scores ranging from 0 to 60 (high mutuality). The measurement of mutuality is based on perceptions of the FCG about their relationship with the person with dementia.²⁷

FCG strain was evaluated by the Modified Caregiver Strain Index (MCSI), a 13-question tool with very good internal and test-retest reliability.²⁸ The MCSI measures strain related to the following domains affected by caregiving: employment, financial, physical, social and time. A positive screen (7 or more items positive) on the CSI indicates a need for more in-depth assessment to facilitate appropriate intervention.²⁸

FCG depression was measured with the Hospital Anxiety and Depression Scale (HADS) subscale for Depression (HADS-D). Scores can range from 0–21 with scores categorized as follows: normal (0–7), mild (8–10), moderate (11–14), severe (15–21).²⁹

FCG Outcome variable: *FCG Anxiety* was evaluated with the seven-item Hospital Anxiety and Depression Scale (HADS) subscale for Anxiety (HADS-A).²⁹ Scores for HADS-A can range from 0–21 with scores categorized as follows: normal (0–7), mild (8–10), moderate (11–14), severe (15–21). The sensitivity and specificity of approximately 0.80 for the HADS and its subscales is very similar to the sensitivity and specificity achieved by the General Health Questionnaire (GHQ), and retest reliability shows a high correlation of $r > 0.80$.^{29, 30}

Patient data included socio-demographic characteristics (age, gender, race/ethnicity, marital status, education, type of residence).

Pre-existing cognitive impairment was established based upon a score of two or greater on the Modified Blessed Dementia Rating Scale (MBDRS) evaluated through an interview with the FCG upon the patient's hospital admission. The MBDRS is an 11-item tool which assesses the patient's competence in performing basic and instrumental activities (e.g. performing activities of daily living, household activities and handling money) with scores ranging from 0 (no dementia) to 17 (profound dementia).²⁶ The BDRS has good discriminative validity in terms of sensitivity, specificity and predictive value; it also has good test-retest reliability and internal consistency.³¹

Delirium was detected using the Confusion Assessment Method (CAM),³² a standardized screening algorithm allowing persons without formal training to quickly and accurately identify delirium. The CAM has four features: 1) acute onset and fluctuating course, 2) inattention, and either 3) disorganized thinking, or 4) altered level of consciousness. The CAM algorithm for the diagnosis of delirium requires the presence of both the first and the second criteria and of either the third or the fourth criterion. The CAM was validated against geriatric psychiatrists' ratings using DSM-III-R criteria and has been shown to have a sensitivity between 94% and 100% and a specificity between 90% and 95%.^{32, 33} The CAM has also been validated in persons with dementia.³⁴

Physical function was measured using the Barthel Index (BI), a 10-item ratio scale that evaluates bowel status, bladder status, grooming, toilet use, feeding, transfer, mobility, dressing, stairs, and bathing.³⁵ The BI is a reliable indicator of functional ability in older adults when administered by face-to-face interview (ICC 0.89) and on testing by different observers (ICC 0.95–0.97).^{36,37} Scores range from 0 to 100 and higher scores are indicative of more independent functioning. Both self-report of pre-admission (2 weeks prior to admission) and admission (baseline) physical function were collected.

Disease burden was estimated based on the Charlson Comorbidity Index.³⁸ This tool assigns weights to comorbid conditions to establish a score (ranging from 0 to 33) and is considered a valid and reliable measure of disease burden.

Qualitative data—A semi-structured interview guide, developed by the researchers and shown in Table 1, was used to explore the experience and perspective of family caregivers. They were asked to describe their experiences with the hospital admission and their response as caregivers. The questions in the interview guide were checked for suitability in two pre-test-interviews and were subsequently slightly modified.

Quantitative analysis

Standard descriptive statistics were used to describe patient and FCG characteristics. Next, linear regression analyses were carried out to identify associations between FCG anxiety and both FCG variables (demographic, quality of the relationship, FCG strain) and patient variables (demographic, delirium, physical function, disease burden). First, univariate regression analyses were conducted to identify the contribution of each variable to FCG anxiety, independently from all the other variables. Second, variables that demonstrated statistical significance in the univariate analyses were entered into a multiple linear regression model using both a stepwise and backward method in order to examine their concurrent influence upon FCG anxiety. This model was refined by discarding any variable found to become non-significant using an increment test, until all variables were found to contribute significantly to the model.

Qualitative analysis

Colaizzi's phenomenological analysis method³⁹ was used for qualitative analysis. Two researchers, the PI and the co-investigator each independently coded the data. First each researcher read through all the transcriptions to get a feeling for them. Then each researcher

extracted significant statements that directly pertained to the research question, i.e., the experiences and responses of FCGs during hospitalization of their family member with AD. The researchers assigned meaning to each significant statement. The two coders discussed and reached consensus on the significant statements and their assigned meanings. Each coder then individually grouped formulated meanings into corresponding themes, and then discussed their decisions jointly until consensus. In order to determine that all significant statements were accounted for, themes were related back to the original statements. When indicated, subclusters were identified within the themes.

Triangulation of data

Quantitative and qualitative data were collected and analyzed separately to produce two sets of findings. The findings from each component of the study were listed on the same page and the researchers examined where findings from each method agreed (converged), offered complementary information on the same issue (complemented), or appeared to contradict each other (showed discrepancy or dissonance).⁴⁰

RESULTS

Quantitative Data

The majority of patients were female (60%); white (96%), widowed (50%), with a mean age of 83.8 (± 6.7). Sixty percent of patients had more than a high school education. Most patients (96%) were admitted from a private residence; the rest were admitted from assisted living. Self-reported pre-admission (two weeks prior to admission) BI was on average 83.1 (± 20.7) and the admission BI was 74.2 (± 25.6). The mean MBDRS was 13.8 (± 9.9). Upon admission, 22 patients (44%) presented with delirium and the average Charlson co-morbidity was 3.8 (± 2.6).

The majority of FCGs were daughters (42%), followed by female spouses/partners (24%). Most FCGs were married (70%); 38 percent were college educated or higher. Fifty percent of FCGs were in the age range of 46–65 and a little more than half (52%) were employed outside the home. Twenty-two percent of the FCGs showed some degree of depression on the HADS-D subscale (mean: 4.2 $\pm$ 3.4; range: 0–12) with 18% demonstrating both anxiety and depression. The mean Mutuality Score was 47.8 (± 11.1 , range 9–60) and the Modified Caregiver Strain Index was 6.5 (± 5.8 , range 0–19).

Table 2 shows that the mean anxiety score on the HADS-A subscale was 7.3 (± 4.5), with 30% of FCGs showing moderate to severe anxiety. Within the set of family caregiver and patient variables investigated, four variables reached significance as predictors of caregiver anxiety. Three patient variables (level of education, dementia severity, and baseline function) and one FCG variable (strain) were found to make contributions to the HADS-A subscale score. More specifically, lower patient educational level, higher dementia severity, lower patient physical function, and higher caregiver strain were predictive of higher anxiety.

Multiple regression analyses combining these four variables yielded a significant model ($F(2, 47) = 6.8, p = .002$) containing two predictor variables, which explained 23% of the score

variance on the HADS-A subscale score (Table 3). The patient's dementia severity and caregiver strain independently contributed significantly to the final model. Higher dementia severity and higher caregiver strain at admission were associated with higher FCG anxiety.

Qualitative Data

The following broad themes describing the experiences and responses of FCGs were identified: 1) added strain; 2) care-related worries; 3) need to be heard; 4) enablers of family caregivers; and 5) family strategies.

Theme 1 Added strain (“major interruption”)—FCGs described the persistent, ongoing stress of caring for a family member, often intensified by the hospitalization. Some described the disruption of hospitalization imposed upon their lives. They reported that hospitalization puts additional demands on their time, interfering with routines and other responsibilities. Some FCGs reported they were experiencing increased fatigue due to increased care needs prior to the hospitalization when the patient was experiencing symptoms of an acute illness. Others described embarrassment related to the patient's behavior (e.g., treatment interference such as attempts to remove lines).

Theme 2 Care-related worries—FCGs described worry about the experience and care of the person with dementia during the hospital stay. One worry related to the patient's experiencing distress and demonstrating behavioral manifestations. Some reported concern that changes in the patient's cognitive status and behavior would not be recognized or would be misinterpreted. They were worried that this would result in delayed treatment and/or discomfort for the patient.

Additionally, FCGs reported worries about the management of common problems that occur in hospitalized older adults. One concern was that pain would not be detected. Some FCGs also stated they were afraid that the patient would fall and therefore did not want the patient to be physically active. A few FCG reported past problems with medication management, specifically medications that cause sedation and/or mental status changes.

FCGs also worried about the potential loss of physical and cognitive function incurred during the hospital stay. Some FCG attributed hospital –acquired deconditioning with bedrest, lack of cognitive stimulation, and longer lengths of stay. FCGs described positive approaches to prevent functional loss, including engagement in meaningful activity (“keeping {the patient} occupied”) and promotion of mobility.

Discharge presented specific anxieties for FCGs. Several worried about their ability to care for the patient at discharge given their own health problems. Additionally, the competing demands of work outside the home and the needs of other family members presented challenges to caring for the patient who might have new and more intensive needs upon discharge.

Theme 3 Keeping vigil—FCG described keeping vigil during the hospitalization to support patient comfort and prevent complications. Vigilance was manifested in a plan for regular visits which could include a schedule of family and friends visitations. FCGs

described meals as important times to be available to assist patients; some FCGs provided assistance with bathing and mobility. For some FCGs calling on the telephone supplemented visits; a few were unable to visit due to health problems and relied solely on telephone updates from staff and calls to the patient.

Theme 4 Need to be heard—Several FCG described the importance of health care staff seeking family involvement in assessment, especially when establishing baseline status. Some reported that it was difficult to convince nursing and medical staff that the patient was experiencing an acute change in mental status. Frustration was also expressed when the FCG provided information and perceived that it was not integrated into decision-making. Conversely, some FCGs reported that they were involved in assessment and care planning. They felt that because of their involvement the outcomes were better for patients, and that they in turn experienced less stress. Some FCG felt that although they wanted to provide the patient history and other information to medical and nursing staff, requests to repeat information multiple times created stress and fatigue.

Theme 5 Enablers of family caregivers—FCGs reported that worry was mitigated when they received information on the patient's condition and plan for diagnostics and treatment. The use of a bedside communication board supported communication with staff and physicians, and involvement in decision-making. FCG were cognizant that staff expertise in the care of older adults supported a positive experience and better outcomes during the hospitalization. The quality of the interaction with both staff and physicians was emphasized, with listening and kindness being very important to the FCG sense of well-being.

Triangulation of quantitative and qualitative data

Both qualitative and quantitative data converge in describing the relationship between two factors (caregiver strain and dementia severity) and anxiety in FCGs of persons with dementia upon admission to the hospital setting. The qualitative data provides complementary information on the nature and sources of anxiety ("worries"), the enablers of FCGs and the strategies employed by FCGs to help cope with anxiety. There are no sources of dissonance in the data.

DISCUSSION

Both quantitative and qualitative findings indicate that increased caregiver strain upon admission contributes to anxiety in FCGs of hospitalized persons with dementia. FCGs describe the stress related to the acute illness (including additional demands) superimposed upon persistent and chronic demands of caregiving (the "24/7"). This finding underscores the advisability of screening FCGs of persons with dementia for strain in order to evaluate the caregiver risk that could respond to interventions (e.g., need for home care resources, need for counseling to deal with certain behaviors), especially after discharge. Education, skills teaching, and a link to community resources e.g. for problem-focused coping, depression screening and treatment, anxiety management and respite, are examples of interventions that can be introduced in acute care and continued in the community setting.

Our future research will evaluate resource deployment, i.e., identifying the appropriate professional to coordinate this evaluation and development of an individualized treatment plan in the busy hospital setting which emphasizes efficiency. Policy implications include reimbursement for family-focused interventions, including family education, in order to promote the sustainability of programs that support and engage family caregivers.

FCG worries (the emotional needs of the patient and the potential for functional decline, falls, pressure ulcers, and manage pain) provide guidance to clinicians' efforts to partner with them in care planning during the hospitalization. Systematically addressing these issues through FCG education as well as individualized care plans has the potential to improve patient outcomes while also mitigating FCG anxiety. FCGs can provide valuable guidance in how to best communicate with the person with dementia and support positive coping. Similar to other research,⁴¹ some FCG discouraged physical activity in an effort to prevent falls. The need to educate FCG about deconditioning as a contributing factor to falls while promoting safe physical activity is apparent. Given that lower baseline function was associated with higher FCG anxiety, and families describe worry about additional functional loss, care plans would ideally emphasize physical activity and early mobility to prevent additional decrements in function. Findings underscore the need to augment the traditional discharge instructions that address medications and medical follow-up with individualized plans for physical activity and self-care.

Several other findings are salient to guiding care delivery to families who are impacted by dementia. Consistent with past research with non-dementia caregivers, sharing of information and involvement with decision-making are very important to family members.⁴² Information about the patient history, including baseline cognition and physical function, comorbidity, and coping is essential to guiding treatment plans including discharge planning. The efficient collection and dissemination of this information among the health care team present logistical challenges in a busy hospital. Systematic methods of sharing information on an ongoing basis regarding diagnostics and treatment as well as bedside care plans can support patient and family engagement.

A workforce that has the specialized knowledge and skill set to work with older adults, is an essential component for system change to provide family-centered care.^{43, 44} The need for education that addresses the clinical and psychosocial care of patients with dementia is generally acknowledged.⁴⁵ However, our findings suggest the need to address the unique needs of FCGs: their emotional response to an acute illness to the care-receiver, identification of and response to risk for caregiver strain, and techniques to provide psychosocial support, communication, and partnership in care. Education and training of the current healthcare workforce as well as future healthcare professionals regarding effective methods to assist and collaborate with family caregivers is called for.

The FCGs' description of the need to be either actively engaged in care or to provide oversight was consistent with Mahoney's concept of vigilance in dementia family caregiving.⁴⁶ Regularly scheduled visits of family and friends appear to be a mechanism to foster shared vigilance. Future research is warranted to examine the role of the primary FCG in coordinating this activity, as well as other care management functions. In order to support

the patient's right to self-direction, this line of inquiry would include methods to ensure that the care preferences of the cognitively impaired older person are not superseded by the FCG.

Limitations

This study has several limitations. The first limitation is related to the sample. Although adequate for a qualitative study, the sample size of 50 dyads provided limited power for a robust quantitative analysis. The participants were mostly well educated and white. Confirming the study findings in a larger, diverse sample, would be informative and extend generalizability. The second limitation is related to measurement. *There is the possibility that other factors (e.g., FCG health, personality, coping style) not evaluated in this study, may have contributed to family anxiety.*

Conclusion

The prevalence of dementia among hospitalized older patients is high and is likely to increase with population aging. The hospital setting will continue to play a role in the health care experience of persons with dementia and their family caregivers. Despite limitations, the results of this study, informed by the views of family caregivers, suggest that caregiver strain upon admission and the patient's baseline physical function significantly influence FCG anxiety. Routine evaluation of caregiver strain and baseline patient function is integral to informing the transitional planning for persons with dementia. The FCG responses suggest that a multi-factorial approach (family-centered policies of partnership in care, staff education addressing the specialized needs of patients and family- members, and attention to promoting functional recovery) may benefit both hospitalized patients with dementia as well as FCGs and warrants future research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Interview Guide

1	What has the experience been like for you to admit your family member to the hospital?
2	What have hospital staff done to help your family member? <ol style="list-style-type: none">a. What has been helpful and why?b. What has been not helpful?c. Is there anything else that could be provided?
3	What have hospital staff done to help you? <ol style="list-style-type: none">a. What has been helpful and why?b. What has been not helpful?c. Is there anything else that could be provided?

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Table 2

Family Caregiver Hospital Anxiety and Depression Scale (HADS) subscale for Anxiety (HADS-A) Anxiety

Mean: 7.3 (± 4.5) Range: 0–17	
	N (%)
None	27 (54)
Mild	8 (16)
Moderate	6 (12)
Severe	9 (18)

Table 3

Univariate and multivariate regression analyses on patient and family caregiver variables for prediction of the Hospital Anxiety and Depression Scale (HADS) subscale for Anxiety (HADS-A)

Variable	B	SEB	β	p
Univariate analyses				
Patient age	-.170	.094	-.253	.050
Patient educational level	-.811	.384	-.292	.040
Patient baseline function	-.073	.030	-.335	.017
Caregiver strain	.277	.105	.355	.011
Final multivariate model				
Patient baseline function	-.062	.029	-.284	.036
Caregiver strain	.241	.103	.309	.024