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The Caregiver Burden of Delirium in Older Adults with Alzheimer Disease and Related Disorders

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Abstract

Objectives: To measure the burden of delirium in older adults with or without Alzheimer disease or related disorders (ADRD)

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1. Study concept and design: TGF, AR, TTH, ERM, RNJ, SKI
2. Acquisition of subjects and/or data: SB, ERM, RNJ, SKI
3. Analysis and interpretation of data: TGF, AR, DMF, PT, YG, EMS, TTH, EM, ERM, RNJ, SKI
4. Preparation of manuscript: TGF, AR, DMF, PT, YG, EMS, TTH, EM, SB, ERM, RNJ, SKI

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Conflict of Interest: The authors have no conflicts

Design: Prospective, observational cohort

Setting: Inpatient hospital, study participants' homes

Participants: A subset (n=267) of older medical and surgical patients and their caregivers enrolled in the Better Assessment of Illness (BASIL) study

Measurements: Delirium burden was measured using the DEL-B instrument (range 0-40, higher scores indicate greater burden) in caregivers (DEL-B-C) and patients (DEL-B-P) one-month after hospitalization. Severity of cognitive impairment (Montreal Cognitive Assessment, MoCA), delirium presence (Confusion Assessment Method, CAM) and delirium severity (CAM-Severity, CAM-S) were measured during hospitalization and at one-month followup. ADRD diagnosis was determined by a clinical consensus process.

Results: For patients with (n=56) and without (n=211) ADRD, both DEL-B instruments had good internal consistency. DEL-B-C scores had a median (interquartile range, IQR) among caregivers of patients with and without ADRD of 9 (5-15) and 5 (1-11), respectively ($p < 0.05$). If the patient developed delirium, caregivers experienced greater burden ($\beta[\text{delirium} \times \text{ADRD}] = -0.29$, $p = .42$), regardless of ADRD status. Further, caregiver burden was modestly correlated with patient MoCA scores (Spearman correlation coefficient, $\rho = -.18$, $p = .01$). Patients with ADRD who developed delirium self-reported less burden than those without ADRD ($\beta[\text{delirium} \times \text{ADRD}] = -0.67$, $p = .044$). As with caregivers, delirium burden was modestly correlated with patient MoCA score ($\rho = -.18$, $p = .005$) and correlated with the CAM-S in patients without ADRD ($\rho = .38$, $p < .001$) but not for patients with ADRD ($\rho = -.07$, $p = .61$).

Conclusions: Delirium resulted in the same degree of increased caregiver burden regardless of whether or not a patient had ADRD, signifying delirium is equally stressful to caregivers, even among those with experience caring for someone with a chronic cognitive disorder. Delirium burden is only modestly associated with degree of cognitive impairment, suggesting that other aspects of delirium contribute to burden.

Keywords

Delirium burden; caregiver burden; patient burden; Alzheimer disease; dementia; ADRD

Introduction

Delirium, characterized by acute impairment of attention and cognition, is common in seriously ill hospitalized older adults^{1,2}, and associated with adverse outcomes³⁻⁵. Older adults with Alzheimer Disease and related disorders (ADRD) are especially vulnerable to developing delirium⁶. Delirium can be burdensome for patient and caregiver^{7,8} owing to the subjective *distress* (i.e., fear, anxiety, suffering) associated with the experiential, emotional, and situational aspects of delirium⁷. ADRD also adversely impacts the health, socialization, and finances of caregivers¹⁰, with elevated stress levels in nearly 60%, depression in 40%⁹, and other burdens^{11,12}. Delirium and ADRD often coexist, but the effect of delirium burden on ADRD patients, and their caregivers, has not been well-studied.

In this paper, we measured delirium burden experienced by caregivers of persons with and without ADRD, and by the patients themselves, using the delirium burden (DEL-B)

instrument¹³, and examined whether delirium burden correlates with cognitive impairment or delirium severity. We hypothesized that caregiver delirium burden is greater for caregivers of ADRD patients, and is positively-associated with severity of patient cognitive impairment. In contrast, we predicted less delirium burden reported by ADRD patients, and in particular less delirium burden as severity of cognitive impairment increases. Finally, we hypothesized that delirium severity is associated with increased burden for both caregivers and patients, regardless of the patients' ADRD status.

Methods

This study was conducted in a subset of patients and family caregivers enrolled in the Better Assessment of Illness (BASIL) study, an ongoing prospective, observational study of 352 older surgical and medical patients and their family caregivers¹⁴. For the purposes of this study, the caregiver was a family member, friend, neighbor, or legal guardian, who knew the patient well enough to be able to answer questions about his/her mental and physical health. The caregiver could be someone already involved in the patient's care, or someone identified at the time of hospitalization who could provide collaborative information. With hospitalization, many patients, regardless of age or cognitive status, have a supportive family member or "caregiver" to provide support (bring items from home, provide company, etc.), even when they did not require one at home.

The total sample included 267 patients and/or family caregivers. Due to incomplete overlap of patient-caregiver dyads (death, refusal, or drop-out), the sample included 243 patients and 214 family caregivers who completed delirium burden measures. ADRD patients were screened for capacity to consent, and written consent was obtained from all participants and/or their proxies. Patients with advanced dementia unable to communicate or interact were excluded.

The BASIL study included an initial in-hospital assessment, daily hospital interviews, in-person interviews at 1 and 12 months after discharge, and medical chart abstraction¹⁴. Delirium burden was measured using the DEL-B instrument¹³ at the 1-month follow-up visit, to allow sufficient time for resolution of delirium, but not so distant that patients and their caregivers could not recall and reflect on their experiences. To ensure accuracy, patients were administered the CAM and had to be CAM-negative before being administered the DEL-B. There are two versions of the DEL-B (see Supplement for details), one for caregivers (DEL-B-C) and one for patients (DEL-B-P).

Delirium status and severity, cognitive function, clinical characteristics and outcomes were assessed by structured interviews and medical records review. Presence of delirium was rated daily during hospitalization by the Confusion Assessment Method (CAM)¹⁶ long form, using brief cognitive testing including the Montreal Cognitive Assessment (MoCA)¹⁵ supplemented by additional cognitive tests (e.g., days of the week and months backwards). The CAM has high sensitivity (94%–100%), specificity (90%–95%), and reliability^{16,17}. Chart evidence of delirium using a validated approach¹⁸ supplemented daily CAM scores to maximize detection of delirium. Delirium severity was measured with the CAM-S¹⁹. Measures of cognitive impairment included the MoCA¹⁵, and the Informant Questionnaire

on Cognitive Decline in the Elderly (IQCODE)²⁰ at baseline and 1-month. The higher MoCA score, recorded at either the baseline or 1-month assessment (to account for potentially falsely low MoCA performance during hospitalization), and the IQCODE, were used to adjudicate the ADRD diagnosis. All participants from the full BASIL cohort (N=352) were assigned a diagnosis of ADRD or no ADRD using a rigorous sequential process (see Supplement for full details).

Statistical Methods

Internal consistency was tested with Cronbach's α . Intraclass correlation coefficient (ICC) was used in a subset of caregivers who completed the DEL-B-C at baseline (during hospitalization) and at 1-month. DEL-B scores were compared between patients with and without ADRD and then between groups classified by delirium (present, del+, or absent, del-) and ADRD (present, ADRD+, or absent, ADRD-) status (i.e. del-/ADRD-, del-/ADRD+, del+/ADRD-, del+/ADRD+), controlling for patient age at hospitalization, sex, and years of education. Statistical significance between groups was tested by the interaction of delirium and ADRD in linear regression. Continuous variables were standardized based on the distribution of the overall sample.

Spearman correlation coefficients (rho) were calculated between DEL-B and MoCA total score (best recorded score at baseline or follow-up) or the CAM-S (peak score). A sensitivity analysis was conducted for the correlations between delirium severity and DEL-B scores after excluding patients without delirium.

Results

Cohort Characteristics

Patients were on average 80.3 ± 6.8 years old. Fifty-seven percent were female, 17% non-white, and education was 14.6 ± 2.9 years¹³. Cohort characteristics by delirium and ADRD status are described in Table 1.

Performance of the DEL-B Instrument

In patients with ADRD (ADRD+), Cronbach's $\alpha = .79$ for DEL-B-C and .75 for DEL-B-P. In patients without ADRD (ADRD-), α was .85 for DEL-B-C and .87 for DEL-B-P. The stability of DEL-B-C over one-month was good for caregivers of ADRD+ (ICC = .68) and ADRD- (ICC = .72) patients.

Delirium Burden Among Caregivers of Persons with Dementia

Average DEL-B-C scores were higher in caregivers of ADRD+ patients compared to caregivers of ADRD- patients by about 1/3 standard deviation unit (SD) (Figure 1a; standardized Beta, $\beta = 0.34$, $p = 0.043$, 95% CI [0.01, 0.67]). In the absence of delirium, DEL-B-C scores did not differ between caregivers of ADRD+ and ADRD- patients ($\beta = 0.29$, $p = .14$, 95% CI [-0.09, 0.67]). Compared to caregivers of del-/ADRD- patients, caregivers of del+ patients reported substantially higher DEL-B-C scores by almost 1 SD with an equivalent degree of increased burden in those with and without ADRD (Figure 1A; del+/ADRD- $\beta = 0.89$, $p < 0.001$, 95% CI [0.50, 1.27]; del+/ADRD+ $\beta = 0.89$, $p < 0.001$, 95% CI

[0.40, 1.37]). Additional increases in DEL-B-C were not observed in caregivers of del+/ADRD+ patients (β [delirium $\times$ ADRD] $=-0.29$, $p=0.42$, 95% CI $[-0.98, 0.41]$). Caregiver burden was modestly correlated with MoCA scores (Spearman's rank correlation coefficient, $\rho=-.18$, $p=0.01$). However, there were no associations between MoCA score and DEL-B-C when the sample was stratified by delirium status (Supplement Table (sTable) 1). For del+ patients, caregiver burden correlated with delirium severity only in ADRD- patients ($\rho=.28$, $p<.001$); DEL-B-C did not correlate with CAM-S peak score ($\rho=.06$, $p=.69$) (sTable 2) or delirium duration (data not shown) in ADRD+ patients.

Delirium Burden Experienced by Persons with Dementia

DEL-B-P scores in ADRD+ patients did not differ from ADRD- patients (Figure 1B; $\beta=-0.14$, $p=.39$, 95% CI $[-0.36, 0.18]$). However, significant group differences emerged after adding delirium and its interaction with ADRD (delirium $\times$ ADRD) into the model (Figure 1B). Compared to del-/ADRD- patients, del+/ADRD- patients had higher DEL-B-P scores by about 1 SD ($\beta=1.01$, $p<.001$, 95% CI $[0.68, 1.34]$). In contrast, neither del-/ADRD+ patients ($\beta=-0.05$, $p=.77$, 95% CI $[-0.41, 0.31]$) nor del+/ADRD+ patients ($\beta=0.28$, $p=0.24$, 95% CI $[-0.19, 0.76]$) had significantly different scores compared to del-/ADRD- patients. The presence of ADRD in patients who developed delirium self-reported less burden by about 2/3 SD units compared to ADRD- patients (β [delirium $\times$ ADRD] $=-0.67$, $p=.044$, 95% CI $[-1.32, -0.02]$). As with caregivers, delirium burden in patients was modestly correlated with patient MoCA score ($\rho=-.18$, $p=.005$; sTable 1) and correlated with the CAM-S in ADRD- patients ($\rho=.38$, $p<.001$) but not for ADRD+ patients ($\rho=-.07$, $p=.61$) (sTable 2).

Discussion

This study investigated quantifiable differences in caregiver and patient burden due to delirium in persons with and without ADRD. The DEL-B had substantial internal consistency estimates²¹ in both caregiver and patient instruments, and the DEL-B-C showed measurement stability over 1-month, demonstrating reliability in a cohort that includes patients with ADRD.

Distress associated with delirium, reflected by an increase in DEL-B-C scores, affects caregivers of patients with or without ADRD to the same extent. While caregivers may be familiar with burden when caring for someone with cognitive and functional impairments due to ADRD, this does not mitigate the additional burden associated with delirium. The modest association of burden with cognitive impairment ($\rho=-.18$, $p=0.01$) suggests that other aspects of delirium (e.g., functional impairments, behavioral disturbances, incontinence, or sleep reversal) may contribute more to caregiver burden. Level of arousal, a strong and specific indicator for delirium, can help differentiate delirium from dementia^{22,23}, although how this feature contributes to burden is unknown. Interestingly, DEL-B-C correlated with delirium severity only in ADRD- patients; perhaps for caregivers with little or no experience caring for someone who is confused, delirium severity is a stronger predictor of burden, whereas caregivers for persons with ADRD already experienced with caring for confused persons, find that aspects of delirium such as new functional

impairments (not captured in the delirium symptom severity score) contributes more towards burden. Factors which determine caregiver burden in delirium are likely to be complex, nuanced, affected by underlying dementia, and are an important area for future investigation. The unpredictability, rapid onset, and potentially ominous effect on recovery and rehabilitation associated with delirium²⁴ may create stressors distinct from the more familiar ADRD burden model of slower more predictable cognitive decline and loss of function^{7,25}. Established approaches of caregiver coping may be inadequate or less defined in an unfamiliar situation²⁶, leaving the delirium caregiver feeling loss of control, shock, fear and distress^{6,27}. Delirium did not increase DEL-B-P scores in del+/ADRD+ patients. This may be due to lack of awareness, anosognosia, insouciance (lack of concern) or poor recollection of distress by ADRD+ persons.

Several limitations of this study should be noted. First, this is a single-site study and generalizability will need to be assessed in future studies. Secondly, while we were able to demonstrate in this brief report measurable differences in delirium burden, further work is needed to frame these changes within a clinical perspective. For example, we did not determine if specific features of delirium burden are more distressing to caregivers of ADRD + patients compared to ADRD- patients, or how long burden attributable to a specific episode of delirium might persist or change over time. Additionally, examining the relationship of potential contributors to delirium burden (e.g., behavioral disturbances, functional impairment, or clinical changes) is important, however this is beyond the scope of the current investigation. These are important additional areas to consider in future studies. Lastly, the determination of ADRD was based on a previously published, thorough and rigorous sequential adjudication process using cognitive testing and medical record review that had been developed following clinical guidelines²⁸ (Supplement). Since chart documentation yielded heterogeneous etiologies for cognitive impairment (e.g., non-specified dementia, Alzheimer's disease, frontotemporal dementia, vascular dementia, or MCI), all etiologies of cognitive impairment were categorized as ADRD and may have under- or over-estimated the true incidence of ADRD in our sample. This is an important limitation of our study, which will be critical to address in future research. Other sources of response bias in caregivers of persons with dementia and delirium such as ethnicity, sex, length of time caregiving, dementia severity, nature of the relationship, and cultural issues were not considered here but are priority areas for future work.

In summary, delirium significantly and substantially increases caregiver burden, regardless of ADRD status. For this reason, burden should be assessed in all caregivers of and patients with delirium. As with ADRD, caregiver and peer support programs, case management, counseling, education and long-term multicomponent programs²⁹⁻³² should be explored as potential approaches to decrease caregiver distress in delirium. It is important to note that the caregiver interventions for delirium will need to be tailored to specific caregiver burden dimensions, and will likely vary widely among caregivers of patients with or without ADRD. Studies are also needed to better characterize the burden of delirium in diverse populations of persons with dementia and in different settings and stages of ADRD. This study underscores the importance of the DEL-B instruments for measuring emotional distress as a quantitative measure of the subjective experience of delirium. The DEL-B may be useful in future studies of risk factors predicting caregiver and patient delirium burden in

persons with and without ADRD and for investigations of the associations between burden and outcomes. Ultimately, we hope this work will lay the foundation for future study targeting prevention and management of delirium burden in caregivers and patients, as an important priority for delirium care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Impact Statement:

We certify that this work is novel clinical research. The human impact of delirium is being increasingly recognized as an important area for clinical research and interventions. We believe that this work represents an important advance to the field.

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(A) Caregiver Burden **(B) Patient Burden**

Figure 1. Delirium caregiver burden (panel A) and patient burden (panel B) by ADRD and delirium status.

Box plots of delirium caregiver burden (DEL-B-C, top panels) and patient delirium burden (DEL-B-P, bottom panels) by ADRD status (left panels) and delirium/ADRD status (right panels). Median [interquartile range] are reported in white text in the respective box. Statistical significance between any clinical group and the control group (denoted by a bracket) is indicated by a horizontal bar (*p < .05, ***p < .001). Statistical analysis controlled for patient age at index hospitalization, sex, and years of education. Statistical significance between delirium/ADRD groups was tested by the interaction of delirium × ADRD in linear regression. Comparisons were first made comparing all groups to the control group (No

ADRD, light purple or Del-/ADRD-, pink) followed by post-hoc comparisons between all groups. For caregivers (panel A), burden was significantly higher in patients with ADRD (dark purple) compared to those without ADRD (light purple), though this was not seen among patients (panel B, left) Post hoc tests for caregiver burden showed that both the Del+/ADRD- (light blue) and Del+/ADRD+ (dark blue) groups had significantly greater burden than Del-/ADRD- (pink, $p<.001$); for patient burden Del+/ADRD- (light blue) had significantly higher burden scores compared to Del-/ADRD- (pink, $p<.001$. ADRD = Alzheimer's disease and related disorders. Del-/ADRD- (pink)= patients with neither delirium nor ADRD, Del-/ADRD+ (red) = patients with ADRD but no delirium, Del+/ADRD- (light blue)= patients with delirium but no ADRD, Del+/ADRD+ (dark blue) = patients with both delirium and ADRD.

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Table 1.**Patient Characteristics Assessed at Index Hospitalization**

Patient Characteristic	Total	Del-/ADRD-	Del-/ADRD+	Del+/ADRD-	Del+/ADRD+
N	267	171	36	40	20
Female Sex, N (%)	153 (57%)	102 (60%)	19 (53%)	25 (63%)	7 (35%)
Non-White or Hispanic, N (%)	45 (17%)	27 (16%)	5 (14%)	9 (23%)	4 (20%)
Age at Baseline, mean (SD)	80.3 (6.8)	79.9 (7.0)	81.7 (6.5)	79.8 (6.0)	82.2 (5.7)
Education (years), median (IQR)	14 (12, 16)	14 (12, 18)	13 (12, 16)	14 (12, 16)	16 (13, 18)
MoCA total score, mean (SD)	18.6 (4.9)	20.5 (3.7)	16.3 (5.0)	15.6 (4.4)	12.3 (4.9)
IQCODE, Proxy Report, median (IQR)	3.2 (3.0, 3.6)	3.1 (3.0, 3.3)	3.7 (3.4, 4.2)	3.3 (3.0, 3.6)	3.7 (3.5, 4.2)
Any ADL impairment, N (%)	64 (35%)	27 (25%)	17 (59%)	10 (37%)	10 (59%)
Charlson Comorbidity Index, N (%)					
(0) 0	71 (27%)	49 (29%)	6 (17%)	9 (23%)	7 (35%)
(1) 1	57 (21%)	39 (23%)	7 (19%)	8 (20%)	3 (15%)
(2) 2+	139 (52%)	83 (49%)	23 (64%)	23 (58%)	10 (50%)
Duration of delirium (days), median (IQR)	0 (0, 0)	0 (0, 0)	0 (0, 0)	1 (1, 2)	2 (1, 3)
CAM-S Peak, mean (SD)	3.8 (2.8)	2.3 (1.3)	3.9 (2.0)	7.6 (2.6)	8.0 (1.8)
ADRD subtype, N (%)		N/A		N/A	
Cognitive impairment (unspecified)	18 (32%)		14 (39%)		4 (20%)
Dementia (unspecified)	13 (23%)		5 (14%)		8 (40%)
Mild Cognitive Impairment	10 (18%)		7 (19%)		3 (15%)
Vascular dementia	6 (11%)		4 (11%)		2 (10%)
Memory loss	5 (9%)		3 (8%)		2 (10%)
Alzheimer's disease	4 (7%)		3 (8%)		1 (5%)
Total, N(%)	56(100)		36(64)		20(36)

ADL = Activities of Daily Living; CAM-S = Confusions Assessment Method – Severity (0 to 19, higher scores indicating more severe delirium; IQCODE = Informant Questionnaire for Cognitive Decline in the Elderly (range 1-5, score of 3=no change, 3.5=dementia). MoCA = Montreal Cognitive Assessment test (0-30, higher scores indicated better performance) total score refers to the highest MoCA score observed either at the index hospitalization or the 1-month assessment

* Percentages in the “TOTAL” row are based on the subsample with ADRD (N = 56) rather than the full study sample.

Note: sample sizes for the patient and caregiver cohort differ (total patient cohort, n=247; total caregiver cohort, n=214). The total “burden” cohort, N = 267, is the sum of patients who had DEL-B data for patient, caregiver, or both. Sample sizes for the following variables are as follows due to missing data; all other variables had no missing data: Proxy IQCODE, N = 186; Education, N = 264; MoCA, N = 266. ADL impairment, N = 181.