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# Factors Associated With Increased Health Care Utilization for Patients With Dementia With Lewy Bodies: A Narrative Review

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#### **Abstract**

Numerous studies have demonstrated that dementia is associated with increased utilization of health care services, which in turn results in increased costs of care. Dementia with Lewy bodies (DLB) is associated with greater costs of care relative to other forms of dementia due to higher rates of hospitalization and nursing home placement directly related to neuropsychiatric symptoms, parkinsonism, increased susceptibility to delirium, and elevated rates of caregiver burden. There is a critical need for researchers to identify potentially modifiable factors contributing to increased costs of care and poor clinical outcomes for patients with DLB, which may include comorbidities, polypharmacy/contraindicated medications, and access to specialty care. Previous research has utilized Medicare claims data, limiting the ability to study patients with early-onset (ie, prior to age 65) DLB. Integrated health systems offer the ability to combine electronic medical record data with Medicare, Medicaid, and commercial claims data and may therefore be ideal for utilization research in this population. The goals of this narrative review are to 1) synthesize and describe the current literature on health care utilization studies for patients with DLB, 2) highlight the current gaps in the literature, and 3) provide recommendations for stakeholders, including researchers, health systems, and policymakers. It is important to improve current understanding of potentially modifiable factors associated with increased costs of care among patients with DLB to inform public health policies and clinical decision-making, as this will ultimately improve the quality of patient care. (J Patient Cent Res Rev. 2024;11:97-106.)

#### Keywords

costs of care; dementia; risk factors; administrative claims data; Lewy bodies

In general, dementia is associated with increased health care utilization and costs, which are largely related to hospitalization and nursing home placement.<sup>1-4</sup> Medicaid and Medicare expenditures for dementia-related care were estimated to be nearly \$290 billion in 2019,<sup>5</sup> and both the incidence of dementia and the number of older adults living with dementia are expected to increase significantly over the next several decades. According to the National Investment Center for Seniors Housing & Care, Medicaid expenditures for nursing home placement averaged approximately \$240 per day, or \$87,000 per

year, per patient in 2020.6 Therefore, delaying nursing home placement for one year or more can significantly reduce lifetime health care expenditures.

Dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD), collectively known as Lewy body dementia, represent the second most common form of dementia following Alzheimer's disease (AD).<sup>7,8</sup> DLB is estimated to represent 4.2%–7.5% of dementia cases, but these estimates may be low due to low diagnostic sensitivity.<sup>9,10</sup> DLB is the most expensive form of dementia due to frequent outpatient visits, high rates of hospitalization,<sup>11</sup> and nursing home placement.<sup>12,13</sup> Patients with DLB have longer hospital stays relative to patients with AD. One study matched patients with DLB 1:4 to patients with AD on age, gender, and cognitive status and found an average of 11 days of hospitalization per year for DLB compared to 7 days for patients with AD.14 Research utilizing 2015 Medicare data in California revealed that the overall average cost

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per beneficiary with DLB was \$22,514, compared with \$13,935 for beneficiaries with AD. After controlling for comorbidities, expenditures for DLB beneficiaries were 31% higher than those with AD.<sup>12</sup>

The high number of hospitalizations and subsequent costs of care for patients with DLB are secondary to a wide variety of neuropsychiatric symptoms, motor impairment, increased risk of delirium, is and high rates of caregiver burden. Io, Io, Io, Although DLB has been associated with more rapid cognitive decline compared to AD, is this has not been consistently demonstrated. There is a critical need for researchers to identify potentially modifiable factors that contribute to increased hospitalizations and ultimately increased costs of care for patients with DLB. However, few studies to date have focused on interventions to reduce health care utilization for patients with DLB, and there are several considerations for research design specific to this dementia subtype.

The goals of this narrative-style clinical review are to 1) synthesize the current literature on clinical features and health care utilization specific to patients with DLB, 2) highlight potentially modifiable factors that may contribute to increased costs of care in this dementia subtype, and 3) provide recommendations for stakeholders, including researchers, health systems, and policymakers, to advance our understanding of potentially modifiable risk factors related to increased costs of health care involving DLB. Understanding these factors can inform interventions to improve patient outcomes.

#### **Literature Search**

In this narrative review of current literature, we highlight current research relevant to health care utilization for patients with DLB including clinical presentation, costs of care, factors related to prolonged hospitalization, medical comorbidities, the use of specific medications, and pharmacologic and nonpharmacologic treatment options. We identified articles searching EMBASE and PubMed for peer-reviewed DLB research studies published in English prior to November 2022. The search strategy included a combination of Medical Subject Headings terms (eg, Lewy body disease, polypharmacy, health care, health care utilization, hospitalization, emergency service, ambulatory care) and keywords (eg, outpatient visit, emergency department, hospitalization, health care cost, service utilization, service use, health care use, delirium, parkinsonism, neuroleptic sensitivity, prodromal, chronic care, nonpharmacologic, frailty, falls, multimorbidity, dementia, caregiver). We also reviewed the reference lists of relevant articles to identify studies.

This narrative review was generated to provide information that may help researchers develop study questions within this population, rather than an allencompassing or a systematic review of the literature on health care involving DLB. As such, all studies related to highlighted topics may not be included.

#### **Risk Factors Identified in Literature**

A summary of risk factors for DLB hospitalization and potential areas for intervention based on the current review of the literature is provided in Table 1. The research supporting these factors are discussed in greater detail below.

**Table 1.** Risk Factors for Hospitalization in Dementia With Lewy Bodies Based on Current Review of Relevant Literature

Susceptibility to delirium

Neuropsychiatric and behavioral symptoms

Medical comorbidities

Falls

Polypharmacy

Underdiagnosis/delayed diagnosis

Limited interaction with specialty care/multidisciplinary services

Inequity in health care access and quality

#### **Clinical Features**

Lack of caregiver support/education

DLB is a heterogenous disorder with a wide variety of symptoms impacting cognition, motor skills, and psychiatric functioning, which have implications for health care utilization. The core clinical features of DLB, as recognized in the 2017 diagnostic criteria, are parkinsonism, visual hallucinations, cognitive fluctuations, and REM sleep behavior disorder. Supportive clinical features include severe sensitivity to neuroleptic medications, postural instability, repeated falls, delusions, hallucinations in nonvisual modalities, depression, anxiety, and autonomic dysfunction, which includes orthostatic hypotension, urinary incontinence, and syncope.<sup>7</sup>

Parkinsonism and gait instability are common symptoms of DLB<sup>7</sup> and are strongly associated with increased costs of health care.<sup>2</sup> Urinary incontinence contributes to caregiver burden and is associated with nursing home placement in this population.<sup>20</sup> The presence of PD-related orthostatic hypotension is associated with increased annual expenses of up to \$15,000 per patient per year

due to injurious falls and hospitalizations.<sup>21,22</sup> Comorbid cardiovascular medical conditions, such as congestive heart failure and hypertension, and medications to treat these conditions can exacerbate orthostatic consequences in DLB and PD, which may further impact costs of care.

#### **Delirium**

Delirium, an acute change in mental status, can be related to infection, medications, dehydration, or other causes. Among older adults, delirium is a risk factor for prolonged hospitalization and increased risk of intensive care unit admission,<sup>23</sup> contributing to higher health care costs.<sup>24</sup> Patients with DLB are at an increased risk of delirium, and delirium may in fact be a prodromal feature of DLB for some patients.<sup>15,25</sup> Individuals with DLB have a greater number of hospitalizations, a greater number of readmissions, and longer lengths of stay due to delirium when compared to other dementia subtypes.<sup>25,26</sup> At least two studies estimated that nearly 50% of the hospitalizations for patients with DLB required treatment of delirium.<sup>27,28</sup>

Given the high prevalence of delirium in DLB, preventative strategies are particularly salient for this population.<sup>23,29</sup> Pharmacological interventions often include the use of antipsychotic medications to manage psychosis and agitation while the root cause of delirium is identified and addressed, and the use of antipsychotics can result in adverse consequences among many patients with DLB.<sup>29,30</sup>

Non-pharmacological strategies are recommended over pharmacological interventions whenever possible and include regular screening for delirium among highrisk individuals, educational programs for medical professionals and long-term care staff, pain control, reorientation, use of hearing and visual aids, adequate hydration, sleep promotion, and strategies to avoid or reduce prescribing medications with anticholinergic properties.31-33 To date, there are few randomized controlled studies designed to examine delirium prevention strategies among older adults with and without dementia.34-36 Lapane and colleagues found that a computerized method of identifying medication interactions and/or medications associated with an increased risk of delirium were effective in reducing incidence rates of delirium among residents in longterm care.<sup>37</sup> However, no specific delirium prevention strategies have been specifically identified for patients with DLB, and further randomized control trials among patients with dementia are needed.<sup>29,38</sup>

#### **Psychiatric and Behavioral Symptoms**

Neuropsychiatric symptoms are common in dementia and are associated with increased medical hospitalization and costs, even after analytical models are adjusted for medical comorbidities.<sup>39,40</sup> Among patients with dementia, those with behavioral disturbances have higher health care costs, an increased number of medications contributing to polypharmacy, and more medical comorbidities than those without behavioral disturbances.<sup>41</sup> The presence of psychosis among patients with parkinsonism is correlated with an increased risk of falls and fractures.<sup>42</sup> This research highlights the importance of nonpharmacologic approaches for managing behavioral symptoms in DLB.

#### Multimorbidity

Medical comorbidities, such as hypertension, hyperlipidemia, and diabetes, are also common among patients with DLB.<sup>43,44</sup> Medicare expenditures are nearly 10 times higher for patients with dementia who have three or more comorbidities (ie, multimorbidity) compared to individuals without a comorbid condition.<sup>45</sup>

Among dementia subtypes, patients with DLB demonstrate similar rates of cerebrovascular disease and diabetes relative to patients with AD but lower rates relative to patients with vascular dementia.<sup>43</sup> However, malnutrition and frailty are more prevalent among DLB relative to other dementia subtypes.<sup>46,47</sup>

Providing interventions aimed at preventing or managing comorbid conditions, frailty, and/or malnutrition, including physical activity with strength training, delirium prevention, and nutrition maintenance,<sup>48</sup> may reduce health care costs in DLB. It is possible that multidisciplinary services, including physical therapy, nutrition services, and clinical pharmacy consultations, may be effective in this regard.

#### **Medications**

There are special considerations and potential contraindications regarding specific classes medications (eg, anticholinergic, antipsychotic, antidementia, or nootropic medications) for individuals with DLB. Cholinesterase inhibitors are used to treat cognitive impairment and behavioral symptoms of DLB and PDD. 49-51 This class of medication has been associated with delayed nursing home placement in patients with DLB.<sup>18</sup> In contrast, anticholinergic medications are associated with an increased risk of cognitive impairment and hospitalization among patients with dementia, 52-54 as well as gait disturbances and falls among older adults.<sup>55</sup> Patients with DLB frequently experience medical conditions for which medications with anticholinergic properties may be used, such as urological, psychiatric, and antiparkinsonian medications.<sup>56</sup>

Among older adults, genitourinary medications with high central anticholinergic properties are associated with an

increased risk of mortality relative to those medications with peripheral activity, but there are no significant differences in hospitalizations or rate of cognitive decline;<sup>57</sup> however, this has not been explicitly studied in DLB. As such, the careful use of anticholinergic medications should be carefully managed and routinely monitored in this population.

Memantine, an NMDA receptor antagonist used for the treatment of dementia, has been demonstrated to be effective in improving cognition and neuropsychiatric symptoms and may also reduce symptoms of REM behavior disorder among some patients with PDD and DLB.58-63 However, some studies have reported worsening hallucinations and delusions with memantine use.

Although antipsychotic medications are prescribed more frequently for patients with DLB than for patients with other dementia subtypes due to the high prevalence of psychotic and other behavioral symptoms,64 antipsychotic medications are typically contraindicated for patients with DLB due to an increased risk of nursing home placement, 18,65 mortality, 66 and susceptibility to neuroleptic sensitivity.<sup>7,28,30</sup> In one study, approximately 80% of the patients with DLB had an adverse reaction to antipsychotic medication with one-half of those patients experiencing severe reactions.<sup>67</sup>

The use of typical antipsychotic medications is associated with longer hospitalization and increased rates of nursing home placement for patients with DLB.<sup>28</sup> Newer, atypical antipsychotics may be helpful for some patients with DLB who do not respond to other interventions for psychosis, 50 whereas other patients may experience adverse reactions. Medications including clozapine, quetiapine, and pimavanserin can cause adverse reactions but typically do not worsen parkinsonian symptoms. In contrast, medications used to treat parkinsonism, such as levodopa, may increase psychiatric side effects, including visual hallucinations.68

Given the sensitivity to multiple classes of medications, nonpharmacologic interventions for behavioral and psychiatric symptoms may be particularly helpful for patients with DLB. Several formal de-escalation strategies have been proposed in the literature. 69-72 Common elements of these models include caregiver and health care provider education in the identification and mitigation of overstimulating environments, hunger, boredom, illness, and/or pain.73-75

Long-term benzodiazepine use has been associated with an increased risk of dementia and a more rapid pace of functional decline among individuals diagnosed with

dementia.<sup>76</sup> However, low doses of benzodiazepines, such as clonazepam, have been demonstrated to be effective in reducing symptoms and therefore injuries related to REM sleep behavior disorder among patients with DLB.68 The risks and benefits of these medications should be carefully weighed.

Finally, polypharmacy is a risk factor for increased utilization and mortality among patients with dementia,<sup>77</sup> as well as functional decline among those with DLB.78 As the disease progresses, patients may require a greater number of prescription medications to manage the wide variety of symptoms associated with this disease.<sup>78</sup> With the accumulation of medications over time, it is possible that patients experience unwanted drug-drug interactions and that unnecessary medications may never be discontinued. Therefore, routine deprescribing interventions, including medication reviews with medical providers and/or clinical pharmacists, should be considered in clinical practice.<sup>79</sup>

#### **Accurate and Timely DLB Diagnosis**

DLB is often underdiagnosed, or the diagnosis can be significantly delayed, 80 resulting in caregivers and families having little understanding of the distressing symptoms of DLB or how to effectively manage them. Delays in dementia diagnosis are associated with increased health care utilization,81 including emergency department visits and hospitalizations that place patients at risk for further adverse outcomes, such as longer lengths of stay, poor post-hospitalization, and earlier nursing home placement.

Patients with undiagnosed DLB may be at an increased risk of hospitalization due to the use of treatments that are contraindicated. For example, patients with DLB often experience psychosis, but they also are more likely to have adverse reactions to antipsychotic medications than individuals with other dementia subtypes.<sup>7</sup>

There have been increasing efforts by the global community to identify DLB in the prodromal phase of the disease. Many of the core clinical features (eg, REM sleep behavior disorder, parkinsonism, cognitive fluctuations, and visual hallucinations) and supportive features (eg, anxiety and autonomic dysfunction) are present prior to developing dementia-level cognitive impairment.82-86 Improving the clinical identification of DLB in the early stages may possibly inform early interventions, which may ultimately improve patient outcomes; however, longitudinal studies are needed.

#### **Use of Specialty and Multidisciplinary Care**

A recent study that focused on DLB and PDD found psychiatric symptoms, such as visual hallucinations, were common causes of hospitalization, but patients frequently did not receive specialty psychiatry consultation.<sup>28</sup> It remains to be investigated whether specialist care improves outcomes after hospitalization for patients with DLB.

Multidisciplinary care may improve the quality of life of patients with dementia and their caregivers; 73,87,88 however, research regarding multidisciplinary services and health care utilization in dementia is mixed, 39,89,90 and randomized control trials of nonpharmacologic treatment with physical therapy and cognitive therapy are lacking among patients with DLB. A list of potential multidisciplinary services is provided in Table 2. To date, the relationship between multidisciplinary care and rates of ER visits and hospital stays has not been explicitly studied in DLB. The presence of motor, neuropsychiatric, and autonomic symptoms in DLB suggests that these patients may benefit more from a multidisciplinary team approach than from other forms of dementia that present with a less complex set of symptoms.

**Table 2.** Multidisciplinary Care Services That May Potentially Reduce Health Care Costs in Dementia With Lewy Bodies\*

Case management
Medication therapy management
Neuropsychological evaluation
Nutrition services
Occupational therapy
Physical therapy
Psychotherapy
Social work consultation
Speech pathology

#### **Socioeconomic and Demographic Considerations**

Ethnic and racial disparities in dementia-related health care have a significant impact on diagnosis, costs, patient outcomes, and caregiver burden. 92,93 For example, dementia specialty care clinics serve a disproportionately high number of Caucasian patients relative to the population demographics. 65 There is limited information regarding the presentation of DLB among women and diverse racial and ethnic groups. 94,95 Although many socioeconomic factors are not modifiable, access to care may be a modifiable factor for some patients. Therefore, improving risk prediction models based on socioeconomic and demographic factors may also positively impact health care utilization. Further research is needed to determine whether there are cultural factors that influence caregiver and patient needs.

Researchers have demonstrated that women with dementia have longer hospital stays than men, <sup>96</sup> and there are differences in readmission rates, which may be related to caregiver distress or other environmental factors. <sup>97</sup> There also appears to be a difference in rates of prescription antipsychotic and benzodiazepine use among men and women with dementia. <sup>98</sup> As mentioned previously, these classes of medication are associated with an increased risk of hospitalization and nursing home placement. Readmission rates and use of psychiatric medications may be particularly salient for patients with DLB due to high levels of caregiver distress <sup>99</sup> and neurobehavioral symptoms. <sup>50</sup> Future studies should strive to expand diversity (eg, sex, race/ethnicity, and rural/urban status) to better inform potential variation in utilization rates associated with DLB.

#### **Administrative Claims Research in DLB**

There are several limitations to the current administrative claims-based utilization studies among patients with dementia, and these studies should be interpreted with some degree of caution. One of the most significant limitations of claims-data research is its reliance on the International Classification of Disease (ICD) codes to classify patients.

As mentioned previously, DLB is often underdiagnosed, posing a significant challenge for claims data research. Although studies have demonstrated DLB is one of the costliest forms of dementia due to frequent hospitalization and length of stay, 12,14 current claims-based studies may underestimate the true economic burden of this disease. This limitation can be mitigated by random chart audits and by utilizing previously established methods of identifying dementia cases from both medical records and claims data to provide a more comprehensive perspective. Integrated health systems are ideal settings for studying DLB, as these systems can merge electronic health record (EHR) and claims data. Furthermore, new methods are available to identify potentially undiagnosed patients with DLB using nonspecific dementia ICD codes in conjunction with ICD codes for the clinical features of DLB (eg, parkinsonism, visual hallucinations, and autonomic dysfunction).<sup>40</sup>

Existing studies focused on dementia and health care utilization have largely relied on Medicare claims data, <sup>100</sup> which may not capture patients with early-onset (ie, prior to age 65) DLB. <sup>101</sup> Combining claims-data from Medicaid, Medicare, and commercial insurance may provide a more accurate picture of the economic burden of DLB. Medicaid data may be particularly important in capturing health care costs for diverse patient populations. <sup>102</sup> Utilizing claims data in conjunction with the Medicare Current Beneficiary Survey, Long Term

<sup>\*</sup>Author suggestions based on this literature review.

Care Minimum Dataset and/or EHR data may also help to capture the full spectrum of costs associated with DLB. Utilization patterns may also vary by specific clinic and hospital systems or by the comprehensiveness of medical insurance coverage. Thus, statistical models may need to account for clustering differences.

Additionally, measures of polypharmacy based solely on the number of medications may not provide specific enough information among patients with DLB. It may be helpful to use standardized measures to assess medication use, which may inform de-prescribing interventions. 103,104 Measures designed to assess anticholinergic medications or anticholinergic burden may provide particularly important information in this population.<sup>52</sup>

#### Remaining Knowledge Gaps and Limitations

There are gaps in our understanding of health care utilization for patients with DLB, but fortunately, there are methods of mitigating some of these limitations. First, future studies focusing on health care utilization should employ methods to identify potentially undiagnosed cases of DLB to gain a more comprehensive picture of the impact of this disease. Administrative claims data linked with electronic medical records may be a useful resource. Second, studies to date have not examined the influence of multidisciplinary care on hospitalization rates in patients with DLB. Providing multidisciplinary care designed to prevent or manage disease-related symptoms and comorbid conditions may reduce health care costs associated with DLB and improve patient outcomes; however, randomized clinical trials are needed to assess the efficacy of these interventions in this population.<sup>91</sup>

Third, studies should examine the impact of delirium prevention and de-prescribing strategies specifically in this population, given the high prevalence of delirium and sensitivity to medications.23 Identification of nonpharmacologic interventions focused on reducing behavioral symptoms may mitigate costly emergency room visits and hospitalizations.74 Finally, additional areas of focus include utilization patterns for diverse patients with DLB, with respect to race, ethnicity, sex, socioeconomic status, and geographic location, to inform policies that benefit all patients with this disease.

Notably, this review was not conducted as a systematic review. Although it is unlikely that publications specifically focused on hospitalization or health care utilization in DLB were missed, utilization studies that focused on patients with dementia, which examined patients with DLB in secondary analyses, may have been omitted. Furthermore, we did not focus on studies specifically designed to measure utilization among

patients with PDD, and this may be a limitation of this narrative review, as these diseases are closely related.

#### **Summary**

As mentioned previously, DLB is associated with greater costs of care<sup>12</sup> and higher rates of utilization<sup>14</sup> compared to other dementia subtypes. However, past studies may have been incomplete in the full assessment of DLB-associated utilization and costs due to underdiagnosis of this disorder. Prior research has shown that, among patients with DLB, health care costs are significantly higher for patients with greater numbers of disease-related symptoms, particularly cognitive fluctuations and delirium.<sup>40</sup>

In this paper, we highlighted the current literature on health care utilization in DLB and made recommendations for future researchers. Based on our review of the literature. focused interventions aimed at reducing hospitalizations for patients with DLB may include medications (eg, polypharmacy and cholinergic medication burden), risk factors for delirium, access to multidisciplinary and specialty care services, and early diagnosis. Research involving populations at risk for disparate care is sparse. It is critical to improve our understanding of the potentially modifiable factors associated with increased costs of care among all patients with DLB to inform public health policies and clinical decision-making, which will ultimately improve outcomes for patients and families.

#### **Patient-Friendly Recap**

- · Dementia is associated with increased use of health care services and therefore increased costs of care, and these costs are worse for patients suffering from dementia with Lewy bodies (DLB) due to higher rates of hospitalization and nursing home placement.
- This article's review aimed pin down the main reasons contributing to increased costs of care and poor clinical outcomes for patients with DLB.
- · Based on the review, focused interventions aimed at reducing hospitalization costs for patients with DLB should consider medications, risk factors for delirium, access to cross-disciplinary and specialty care services, and early diagnosis.

#### **Author Contributions**

Study design: Wyman-Chick. Data acquisition or analysis: all authors. Manuscript drafting: Wyman-Chick. Critical revision: all authors.

#### **Conflicts of Interest**

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