Disability-Associated Economic Burden Among Patients with Wilson's Disease in South Korea: A Nationwide Cost-of-Illness Study

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BACKGROUND

Wilson's disease (WD) is a rare inherited disorder causing copper accumulation that often leads to neurological or hepatic disability. Despite treatment advances, WD patients with disabilities experience greater challenges in daily life and economic activity. However, evidence on disability-related differences in the total economic burden of WD remains limited, particularly in South Korea.

OBJECTIVES

This study aimed to **quantify and compare** the annual per-capita and national all-cause economic burden of Wilson's disease patients **with and without disability** in South Korea, and to **assess the impact** of disability on healthcare utilization and total societal costs (including direct medical, non-medical, and productivity losses) using a **nationwide claims dataset** from 2019.

METHODS

STUDY DESIGN & DATA SOURCE

A cross-sectional cost-of-illness study was conducted using 2019 customized claims data from National Health Insurance Service (NHIS) of South Korea. The dateset included all patients with a confirmed diagnosis of **Wilson's disease (ICD-10: E83.0)** and registered in the **Special Government Subsidy (V119)** program for rare diseases. Each patient record contained demographic information, healthcare utilization, and medical expenditure data from both National Health Insurance (NHI) and Medical Aid programs.

STUDY POPULATION

All WD patients were categorized by **disability registration status** according to the national disability registry. The registry provides official certification of physical or neurological impairments graded from 1 (severe) to 6 (mild) under the Korean Disability Welfare Act. Baseline characteristics including age, sex, income level, insurance type, and Charlson Comorbidity Index (CCI) were compared between the two groups.

COST COMPONENTS & PERSPECTIVE

Costs were estimated from a **societal perspective**, including **direct and Indirect costs. Direct medical costs** includes inpatient, outpatient, and drug expenditures covered or not covered by NHI. **Direct non-medical costs** includes caregiver and transportation expenses. **Indirect cost** includes productivity losses due to hospitalization and outpatient visits, estimated using the human capital approach based on national wage statistics. All costs were expressed in **2019 U.S. dollars** (USD) using the average annual exchange rate (₩1,165.65 per USD).

STATISTICAL ANALYSIS

Descriptive statistics summarized baseline and cost characteristics.
Normality was tested using the Shapiro–Wilk test; group comparisons were performed using t-tests for parametric and Wilcoxon rank-sum tests for non-parametric data.
To evaluate the independent effect of disability on total costs, **generalized linear models (GLM)** with a **gamma distribution and log link** were applied, adjusting for age, sex, income level, and CCI.
A *p*-value < 0.05 was considered statistically significant.

RESULT

STUDY POPULATION AND BASELINE CHARACTERISTICS

Of **1,462 patients with Wilson's disease** (WD) identified in South Korea in 2019, **21.5% (N=314)** were registered as having a **disability** (Figure 1).
Disabled patients were **more socioeconomically vulnerable**, showing a higher proportion enrolled in **Medical Aid programs (19.7% vs. 2.6%)** and in the **low-income group (45.5% vs. 23.4%)** compared with non-disabled patients.

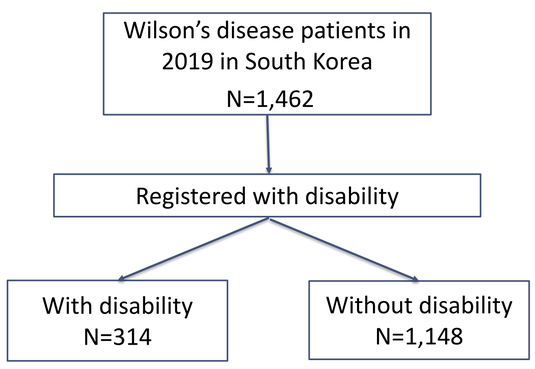

Figure 1. Study population flow diagram

These patterns indicate limited employment capacity and greater dependence on public health support.
In terms of **clinical characteristics**, the disabled group had a **higher comorbidity burden (CCI ≥ 1: 26.1% vs. 18.9%; p = 0.0151)**, suggesting greater disease complexity and potential for higher healthcare needs (Table 1).
Overall, WD patients with disabilities represented **a clinically more fragile and socially disadvantaged subgroup**, warranting focused policy and healthcare management attention.

HEALTHCARE UTILIZATION

Annual hospitalization rates were significantly higher among disabled WD patients **(33.4% vs. 15.5%, p<0.0001)**, with longer **inpatient stays (8.5 vs. 5.8 days, p<0.0001)** and more **outpatient visits (26.0 vs. 17.1 visits/year, p=0.0006)** (Table 2).

Disabled patients also experienced **2.6 times more hospital admissions per hospitalized patient (5.5 vs. 2.1 admissions, p<0.0001)** and demonstrated **slightly higher medication adherence rates (90.5% vs. 73.2%, p=0.0325).**

Overall, these findings suggest that WD patients with disabilities require **more intensive and continuous medical care,** reflecting greater healthcare dependency and disease management burden compared with non-disabled patients.

Table 1. General characteristics of WD patients by disability in 2019 in Korea

	No. patients (%)		
Characteristics	**Disabled**	**Non-disabled**	***p-value***
No. of patients with WD	314 (21.48)	1,148 (78.52)	
Gender			<.0001
Male	188 (59.9)	647 (56.4)	
Female	126 (40.1)	501 (43.6)	
Type of NHS program enrolled in			<.0001
National Health Insurance	252 (80.3)	1,118 (97.4)	
Medical Aid	62 (19.7)	30 (2.6)	
Income level[a]			<.0001
High	97 (30.9)	500 (43.6)	
Middle	66 (21.0)	361 (31.4)	
Low	143 (45.5)	269 (23.4)	
NA	8 (2.5)	18 (1.6)	
Charlson Comorbidity Index Group			0.0151
Healthy (0)	232 (73.9)	931 (81.1)	
Mild (1)	73 (23.2)	187 (16.3)	
Moderate to severe (≥2)	9 (2.9)	30 (2.6)	

[a]Income levels were categorized into three groups based on the 20 percentile tiers of National Health Insurance premiums. The low income includes Medical Aid recipients and those in percentiles P1 to P6, middle income covers P7 to P13, and high income includes P14 to P20, with each percentile representing a 5% distribution range.

Table 2. All-cause healthcare utilization characteristics

All-cause healthcare utilization characteristics	**% or mean (±SD)**			
	All patient included(N=1,462)			
	Disabled	**Non-disabled**	**ratio**	***p-value***
% of WD patients experiencing hospitalization	33.44%	15.51%	2.2	<0.0001
No. of outpatient visits per patient	25.97±30.38	17.05±15.95	1.5	0.0006
No. of hospital admissions among those hospitalized	5.52±11.92	2.10±2.88	2.6	<0.0001
No. of inpatient days per admission patient experiencing hospitalization	8.52±8.64	5.75±6.00	1.5	<0.0001
Medication adherence rate (%)	90.47%	73.24%	1.2	0.0325

ECONOMIC BURDEN BY DISABILITY STATUS

From a societal perspective, the annual per-capita all-causes costs for WD patients with disabilities was **2.85 times higher** than for those without disabilities **($12,831 vs. $4,510, p<0.0001)** (Table 3). Disabled patients incurred greater **direct costs (2.69-fold)** and **indirect costs (3.43-fold)**, mainly driven by **inpatient services (7.06-fold)**, **caregiver expenses (8.43-fold)**, and **productivity loss due to inpatient care (9.76-fold)**.

Non-NHI-covered medical and **non-medical costs** (e.g., transportation and caregiving) also accounted for a larger proportion of total spending among disabled patients.
Overall, **all-cause direct and indirect costs** were consistently elevated across nearly every category, demonstrating a markedly greater **economic vulnerability and healthcare dependency** among disabled WD patients in South Korea.

Table 3. Per-capita cost of WD patients by disability in 2019 in Korea

	Per-capita cost, USD Society Perspective			
	Disabled (N=314)	**Non-disabled (N=1,148)**	**Ratio[a]**	***p-value***
Total costs (direct and indirect costs)	12,831.37	4,509.76	**2.85**	<.0001
Direct costs	9,538.01	3,548.47	2.69	<.0001
NHI-covered medical costs	7,571.68 (59.0%)	3,180.64 (70.5%)	2.38	<.0001
Inpatient services	4,157.67	589.03	**7.06**	<.0001
Outpatient services	2,404.72	1,582.33	1.52	<.0001
WD-related outpatient drug costs	1,009.28	1,009.28	1.00	-
Non-NHI-covered medical costs	242.23 (1.9%)	101.75 (2.3%)	2.38	<.0001
Non-medical costs	1,724.10 (13.4%)	266.07(5.9%)	**6.48**	<.0001
Inpatient transportation	39.49	6.96	**5.67**	<.0001
Outpatient transportation	110.01	72.25	1.52	0.0006
Caregiver's costs	1,574.60	186.86	**8.43**	<.0001
Indirect costs	3,293.36 (25.7%)	961.29 (21.3%)	3.43	<.0001
PL due to inpatient care	2,127.46	217.97	**9.76**	<.0001
PL due to outpatient care	1,165.90	743.32	1.57	<.0001

[a]Ratio represents the relative cost difference between disabled and non-disabled individuals, indicating how much higher the costs are for disabled individuals compared to non-disabled individuals.

CONCLUSION

Disability among WD patients is associated with significant socioeconomic vulnerability and disproportionate healthcare costs. These findings highlight the need for targeted care coordination and support strategies to mitigate the disease burden in high-risk subgroups.
In particular, ensuring equitable access to medical, rehabilitative, and social welfare resources could reduce long-term societal costs.
Future studies should further evaluate cost-effective interventions and longitudinal outcomes to inform sustainable policy decisions for rare disease populations..

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