



BURDEN OF RARE DISEASE

a literature review

MEDICAL COSTS

\$69,275

The average cost **per hospital stay** for an individual with a rare disease is **\$69,275**.¹

\$28,913

The average **annual medical cost** for an individual with a rare disease is **\$28,913 more** than an individual without a rare disease.²

\$4,670

Individuals with a rare disease typically pay **\$4,670** for **emergency room** visit charges.¹

FINANCIAL HARDSHIPS

Individuals with a rare disease and their caregivers may experience the following changes to their jobs:²

Frequent absences from work

Unproductive days due to illness

Forced early retirement

FINDING A DIAGNOSIS

On average, rare disease patients wait **6.3 years** before receiving a **confirmed diagnosis**, and **are often misdiagnosed**.³

6.3 years

Finding a diagnosis may require **traveling far from home** and **visiting many medical specialists**.⁵



Many factors may complicate a diagnosis such as:⁴

Lack of knowledge of the rare disease

Misdiagnoses

Lack of available diagnostic tests

Lack of accessibility to medical specialists

Symptoms overlap with other diseases

TREATMENT & MANAGEMENT



No treatment may be available⁵



Limited number of treatments are available for rare disease⁵



5% of rare diseases have FDA approved treatments⁴



Treatments may be expensive⁵



The average number of specialists that an individual with a rare disease sees is 17.³



Individuals with a rare disease tend to have longer hospital stays¹

OTHER BURDENS



Individuals with a rare disease may suffer from social stigmas that may not allow them to participate in everyday activities.⁵



Lack of data sharing regarding an individual's medical history, disease progression, treatment, interventions, and outcomes can lead to difficulties with advancing diagnostics and treatments.⁵

REFERENCES

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