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

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

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

Many factors may complicate a diagnosis such as:

- 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 available \(^5\)
- Limited number of treatments are available for rare disease \(^5\)
- 5% of rare diseases have FDA approved treatments \(^4\)
- Treatments may be expensive \(^5\)
- 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 stays \(^1\)

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. \(^5\)

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REFERENCES


4. United States Government Accountability Office. Rare Diseases Although Limited, Available Evidence Suggests Medical and Other Costs can be Substantial, October 2021. Available at: https://www.gao.gov/assets/gao-22-104235.pdf