

CAN YOU HEAR US NOW? THE ECONOMIC IMPACT OF RARE DISEASE IN THE U.S.

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BACKGROUND

Rare diseases, defined in the United States (U.S.) as conditions with a prevalence of <200,000 people, are often complex and costly to treat for patients and health care systems. The impact of rare disease is felt broadly, with nearly 7,000 unique conditions collectively affecting over 30 million people in the U.S. (~10%). Moreover, the economic burden of a single rare disease can be massive, with lifetime treatments costing patients millions of dollars. However, the collective footprint of health care utilization and resource allocation by rare disease patients remains poorly understood. Therefore, health care cost and utilization was analyzed using hospital discharges, inpatient length of stay and all associated costs to estimate the overall economic impact of rare disease.

OBJECTIVE

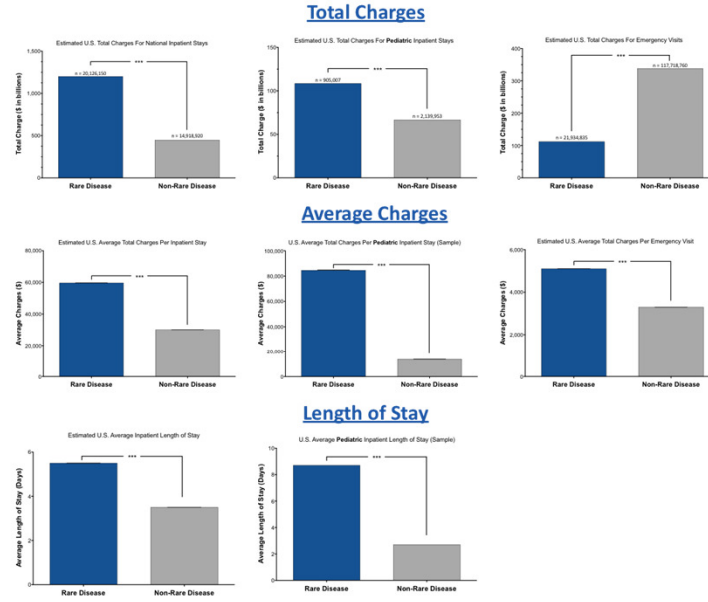
To estimate health care spending and utilization by rare disease patients for a single year in the U.S.

METHODS

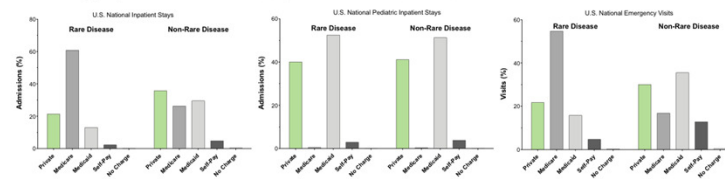
2016 Healthcare Cost and Utilization Project (HCUP) national databases were used to extract hospital care data. HCUP databases include a random sample of 20% of all inpatient hospitalization and emergency data compiled from encounter-level information provided by all payers across 47 states and the District of Columbia. Total charges for the National Inpatient Stay and National Emergency Database were multiplied by 5 to provide a national estimate. The Kids Inpatient Database is sampled differently and was not multiplied. Rare disease was characterized by the 2298 available ICD-10 codes linked, which were derived from a structured and machine computable rare disease reference database (Orphanet) to characterize health care utilization by rare disease patients compared to the non-rare population. Non-rare includes both common and rare conditions without a unique ICD-10 code.

RESULTS

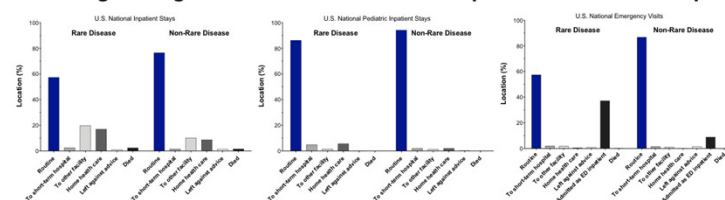
1. Inpatient and emergency visits are substantially higher for rare disease patients



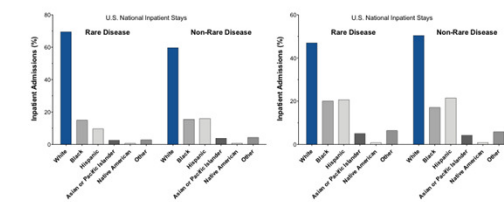
2. Primary payer of rare disease patients is medicare



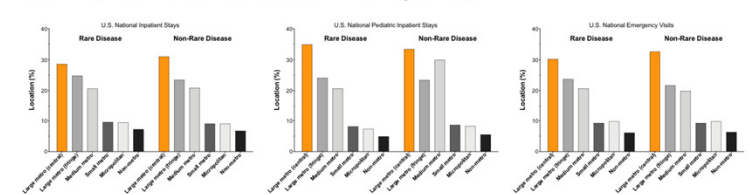
3. Discharge to high cost locations is more frequent for rare disease patients



4. Hispanic population has disproportionately fewer rare diagnoses



5. Similar utilization across community sizes



CONCLUSIONS

- Cost of care for rare disease is massive**
 - Rare disease has an estimated \$1.2 trillion impact on inpatient care in U.S.
 - Ave. cost per discharge was \$59,631 for rare patients and \$30,005 for others
 - Ave. cost per discharge in pediatrics was \$84,574 for rare disease patients compared to \$13,781 for all others
- Rare disease patients utilize medicare at a high rate**
 - 61% of rare disease patients compared to 26% of non-rare have medicare for primary payer for adult inpatients
 - 55% of rare patients seeking emergency care have medicare for primary payer compared to 17% of non-rare
- Discharge status is markedly different for rare disease patients**
 - 37% of rare disease patients were transferred to skilled-nursing or required home health compared to 19% of non-rare patients
 - 50% more adult rare disease patients died during their inpatient stay

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