EE244

Healthcare resource utilization and costs in patients with Alagille syndrome using population-based healthcare data from South Korea

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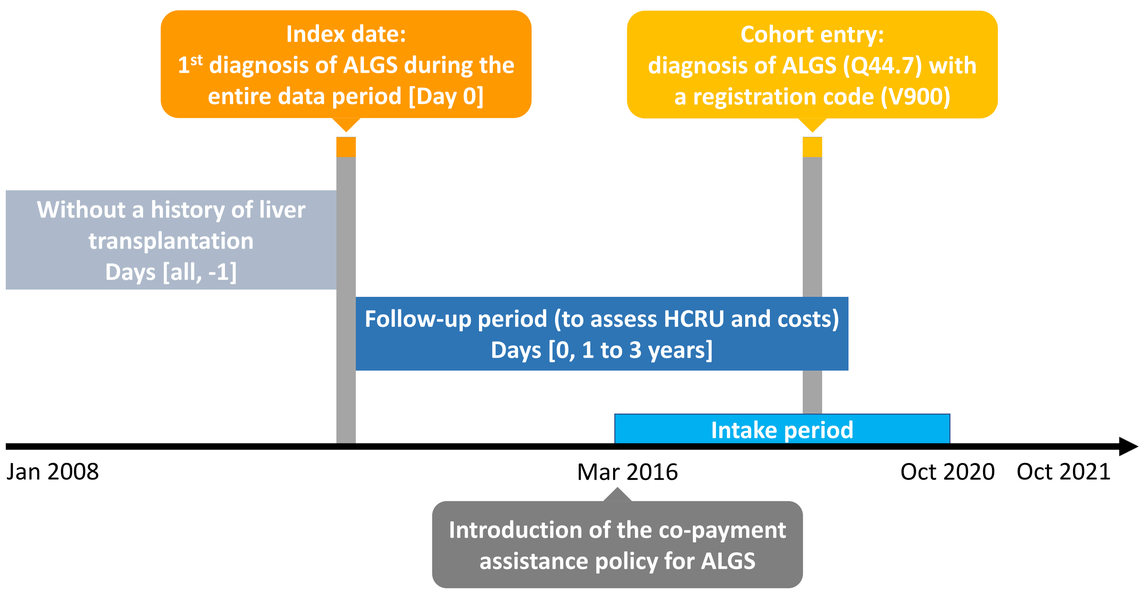
INTRODUCTION

- Alagille syndrome (ALGS) is a rare genetic disorder characterized by the malfunction of multiple systems, including the liver and heart.
- It encompasses challenging symptoms that necessitate frequent clinical intervention, leading to a financial burden among pediatric patients.
- This study aimed to investigate the utilization of healthcare resources and associated costs in patients with ALGS, utilizing population-based healthcare data that encompassed the entirety of ALGS patients in South Korea.

METHODS

- Study design: A retrospective cohort study
  - In South Korea, patients diagnosed with ALGS have been registered under the co-payment assistance policy for rare and incurable diseases since March 1, 2016. This registration system allows for the specific identification of these patients through the use of a unique registration code (V900). Consequently, we have chosen patients diagnosed with ALGS (Q44.7) and possessing a registration code for the co-payment assistance policy (V900) between March 2016 and October 2021.
  - As ALGS is a congenital condition, we have established the index date as the date of the initial diagnosis of ALGS (Q44.7) throughout the entire data period.



Abbreviations: ALGS, Alagille syndrome; HCRU, healthcare resource utilization.

- Data source
  - Health Insurance Review & Assessment Service (HIRA) Database including the entirety of ALGS patients in South Korea from January 2008 to October 2021
- Study population: patients with ALGS
  - Patients diagnosed with ALGS (Q44.7 [other congenital malformations of liver]) with a registration code (V900 [co-payment assistance for extremely rare diseases]) between January 2008 and October 2020
  - Patients without a history of liver transplantation (defined by procedure code of Q80*) prior to the index date
- Outcome measures
  - Hospital visits: annual length of inpatient stay and the number of outpatient visits
  - Direct healthcare costs: annual costs of care associated with ALGS per patient

  ➔ <u>Assessed during the first, second, and third year from the index date</u>
- Statistical analysis
  - Descriptive analysis: mean and standard deviation for continuous variables and number and percentage for categorical variables
  - All analyses were performed using SAS® Enterprise guide version 9.4.

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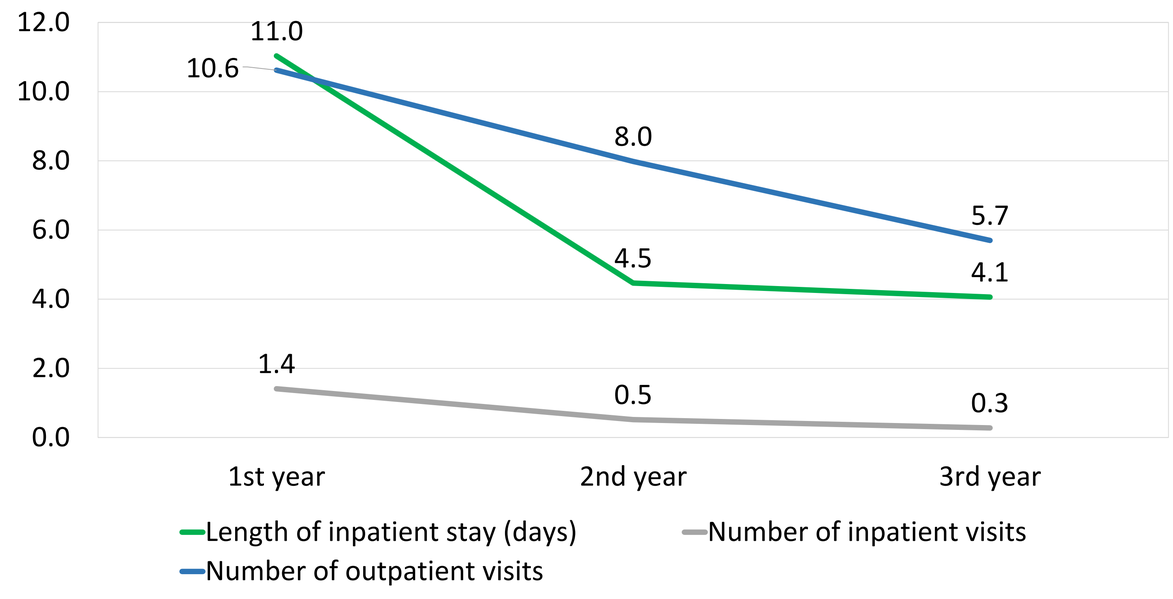
RESULTS

- Baseline characteristics of 67 patients with ALGS

Characteristics	Patients with ALGS (n=67)
Age, years	5.3 ± 6.3
Female	26 (38.8%)
Type of Insurance	
National Health Insurance	61 (91.0%)
Medical Aid	6 (9.0%)
Days between the first diagnosis of ALGS and registration for the co-payment assistance program	1548 ± 1537
Most prevalent comorbidities identified within the total prescriptions	
Pure hypercholesterolemia	4.6%
Chronic hepatitis, unspecified	3.9%
Juvenile rheumatoid arthritis	2.8%
Disorders related to short gestation and low birth weight	2.7%

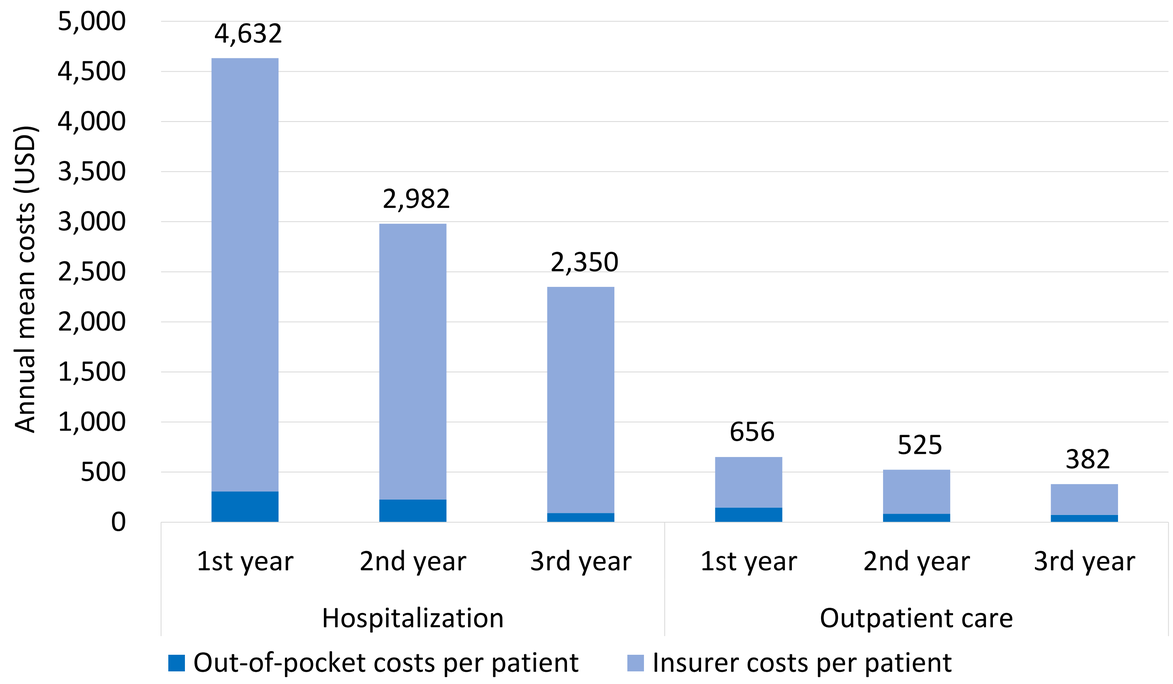
Abbreviations: ALGS, Alagille syndrome; SD, standard deviation

- Hospital visits of patients with ALGS



✓ Over the course of the initial, second, and third years, there was a sustained utilization of healthcare services in both inpatient and outpatient facilities.

- Direct healthcare costs of patients with ALGS



✓ Hospitalization incurred higher total care costs in comparison to outpatient care.
✓ Over the course of the 3-year follow-up period, total care costs for both hospitalization and outpatient care remained elevated.
✓ Outpatient care exhibited higher copayment rates (15.9–22.2%) when contrasted with hospitalization (3.9–7.6%).

CONCLUSIONS

- Pediatric patients with ALGS in South Korea experience persistent utilization of healthcare services and the accompanying costs, that can place a substantial burden on them and their families.
- ***Given that the practical management of ALGS largely relies on the administration of best supportive care, such as ursodeoxycholic acid, the implementation of an effective treatment strategy has the potential to alleviate the burden associated with ALGS.***