Socio-economic burden in patients with rare diseases in Hong Kong

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Introduction

- The socio-economic burden of rare diseases is extremely important for healthcare planning but difficult to estimate.
- The burden of rare diseases comprises an economic dimension.
- The inpatient healthcare burden of the rare disease population was estimated to be HK$1,594,339,530 i.e. 4.3% of the total inpatient costs under the Hospital Authority in 2015-2016.
- Costs of rare diseases is beyond the immediate observable healthcare expenditure; it can be incurred through non-healthcare formal and informal costs and indirectly through productivity and opportunities lost.
- The socio-economic burden of rare diseases is unknown in Hong Kong.

Methods

- We have developed, contextualised, and translated the Client Service Receipt Inventory (CSRI-Ra) to collect direct and indirect cost-related data in the rare disease population in Hong Kong.
- The CSRI-Ra was distributed to independent rare disease patients and carers via multiple rare disease organisations and patient groups.
- Costs were estimated from the societal perspective using a bottom-up approach.
- Data collected for the 6 months were extrapolated to the entire year, allowing the mean annual costs to be estimated per patient.
- Estimated direct and indirect costs of rare diseases based on (i) inpatient admission, (ii) patient’s and unpaid carer’s lost of productivity, and (iii) paid carer

Results

- A total of 276 independent participants (162 rare disease patients and 114 carers of patients with rare diseases) were recruited between 25 April and 6 August, 2020
- Covered 118 unique rare diseases
- 74% rare disease patients required care from a paid or unpaid carer.
- Each rare disease patient requires an average of three rare disease-related inpatient days annually.
- Job opportunity affected in 60% of patients, and 61% of carers, which included unemployment, changed from full-time job to part-time job, and early employment.
- Due to patient’s rare disease condition, patients were employed were required to take an annual average of five days of annual leave, and carers were required to take an average of 15 days of annual leave.

Total annual cost of HK$22,771,049
Minimum average of HK$82,504 per patient per year

Conclusion

- The pilot study demonstrated the feasibility of using CSRI-Ra in Hong Kong to estimate the direct and indirect costs of rare diseases.
- The socio-economic burden of rare diseases in Hong Kong is estimated at a minimum of HK$82,503 per patient per year. With further data analysis including other public and private healthcare services, the cost of rare diseases will definitely increase.
- This study reflects the importance of rare diseases in health policies.
- It provides a framework for long-term monitoring for efficient and effective healthcare planning.

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Reference and Contact Details

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