

Estimating the broader fiscal impact of rare diseases using a public economic framework: A case study applied to hereditary transthyretin-mediated (hATTR) amyloidosis

Mark P. Connolly (1), Saswat Panda (1), Julien Patris (2), Bouke P.C. Hazenberg (3)

1.Global Market Access Solutions Sarl, St-Prex Switzerland, mark@mmasoln.com

2.Anylam Pharmaceuticals, Strawinskylaan 3051 1077 ZX Amsterdam, The Netherlands

3.Department of Rheumatology & Clinical Immunology, University Medical Center Groningen, Groningen, The Netherlands

Theme 5; Poster Number 190

Background

The burden of health conditions is often measured from the healthcare perspective in terms of direct health costs attributed to a medical condition at specific stages of the disease and attributed health costs that stop at death or remission. There is a broader perspective that can be applied to healthcare interventions using human capital economics that is seldom considered. This perspective can reflect the impact of health on the government finances based on lifetime taxes paid and demand for public benefits linked to disability status attributed to health status [1]. Rare diseases can have fiscal impacts on government finances that extend beyond expected healthcare costs. Conditions preventing people from achieving lifetime work averages will influence lifetime taxes paid and increase dependence on public income support. The aim of this study was to apply a public economic (fiscal) framework to a rare disease taking into consideration a broad range of costs that are relevant to government in relation to transfers received and taxes paid.

Methods & Data

A fiscal cost model was developed for estimating the consequences of hereditary transthyretin-mediated (hATTR) amyloidosis in The Netherlands. The fiscal calculator estimates the difference between the average general population (GP) and disability compared to individual hATTR amyloidosis patient journeys. The analysis estimates lifetime direct and indirect taxes paid in both cohorts and incremental differences in disability payments, old-age pensions, and healthcare resource use costs. The model estimates the average fiscal life course for the general population (GP) adjusted for age-specific mortality. Age-specific earnings, labor force participation, unemployment, old age pension, and disability pension figures were obtained from the Statistics Netherlands' data portal [2]. Health costs were based on best supportive care excluding liver transplantation and TTR tetramer-stabilizing treatment in which we applied estimated resource use patterns by polyneuropathy disability (PND) score to known cost tariffs. The healthcare costs for those in the non-hATTR amyloidosis population were derived from the PAID (Practical Application to Include future Disease costs) calculator, version 1.1, a tool to estimate per capita indirect medical costs for the Netherlands [3]. To reflect variation in the fiscal life course for people with hATTR compared to the GP, we apply two likely scenarios that influence lifetime work and disability support (inset below).

Scenario 1 (S1)	Early disease onset, at age 45 at PND state 1, with a median progression through PND states, and death at age 55 at PND state 4, without severe cardiomyopathy.
Scenario 2 (S2)	Early disease onset, at age 45 at PND state 1, with a slow progression through PND states, and death at age 65 at PND state 4, without severe cardiomyopathy.

Results

Based on lifetime work activity and associated earnings, the taxes paid per person in the GP between the ages 40 and 80 are estimated to be €319,922. In contrast, lifetime taxes paid for hATTR S1 and S2 were estimated to be €139,111 and €195,785, respectively, based on likely reductions in direct and indirect taxes paid. These estimates are based on productive life-years lived of 20.2, 6.6 and 9.7 for GP, S1 and S2, respectively.

The lifetime disability benefits received in the GP were estimated to be €2,150 per person. For those with hATTR S1 and S2 the likely disability benefits required based on reduced lifetime work were estimated to be €180,949 and €285,355, respectively.

References & Disclosure

1. Connolly MP., et al., Value Health, 2017. 20(2): p. 273-277.
2. CBS Statline
3. PAID - iMTA [<https://www.imta.nl/paid>]

Study sponsored by Anylam Netherlands

Table 1: Estimated per person fiscal impact between the ages 40 – 80 attributed to GP and patients with hATTR amyloidosis in different disease presentation scenarios

	GP	hATTR S1	hATTR S2
Disability & Pensions	€132,232	€180,949	€ 285,355
Health costs	€206,098	€ 269,076	€ 656,129
Total transfers	€338,330	€450,025	€ 941,483
Lifetime earnings	€577,114	€ 247,559	€ 348,952
Direct tax	€229,148	€ 100,172	€ 140,898
Indirect tax	€ 90,774	€ 38,939	€ 54,887
Gross tax	€ 319,922	€ 139,111	€ 195,785

Following diagnosis of hATTR, people have significant fiscal impact in terms of transfer costs (black area Fig. 1 & 2). Due to reduced work activity and earnings a significant change in lifetime taxes are also observed compared to general population (Fig. 1 & 2 dark grey compared with white area).

Figure 1: Fiscal life course diagnosis hATTR age-45 (S1) compared to GP

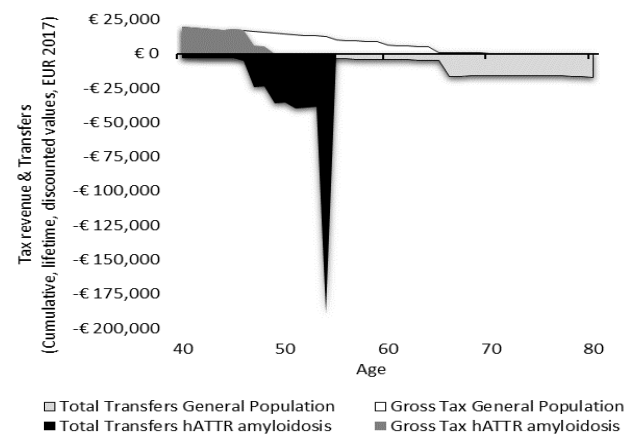
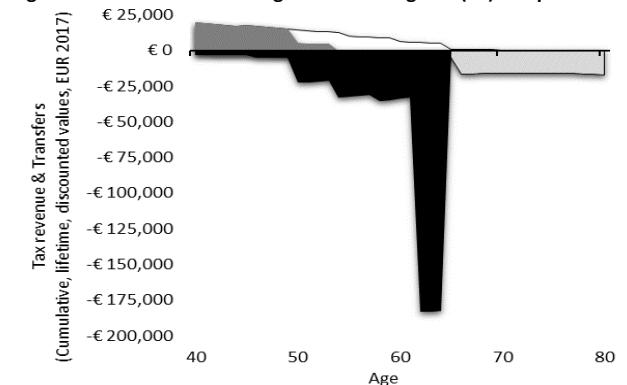


Figure 2: Fiscal life course diagnosis hATTR age-45 (S2) compared to GP



Conclusion

The fiscal analysis illustrates how health conditions influence not only health costs, but also the cross-sectorial public economic burden attributed to lost tax revenues and public disability allowances. Due to the progressive nature of hATTR amyloidosis, public costs including disability increase as the disease progresses resulting in reduced lifetime work activity and consequently reduced lifetime taxes paid. The results suggest that halting disease progression early in the disease course would generate fiscal benefits beyond health benefits for patients. This analysis highlights the fiscal consequences of diseases and the need for broader perspectives applied to evaluate health conditions.