

The disability adjusted life years (DALYs) and economic burden due to haemophilia in Belgium

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Introduction & Objectives

Haemophilia is a rare hereditary haemorrhagic disease that requires regular intravenous injections of clotting factor concentrates. This study sought to **estimate the health and economic burden of haemophilia in Belgium**.

This is the first study of its type to be conducted, and reflects the European and Belgian authorities' growing interest for haemophilia as part of their **planning for rare diseases**.

Material & Methods

A probabilistic model was developed in order to estimate the lifetime haemophilia burden for the 2011 birth-year Belgian cohort. The health burden was initially expressed in terms of **disability-adjusted life years (DALYs)**, this being the number of healthy life years lost due to both disability and premature mortality. An incidence perspective was used in line with World Health Organization recommendations. The economic burden calculated from **direct and indirect haemophilia-related costs** was expressed in euros. Data were drawn from the literature if none were available from federal institutions or health insurance. Disability weights for DALY calculation were derived using generic quality-of-life tools compared to population norms. Analyses were stratified according to haemophilia type and severity. Scenario analyses using different age weighting and time discounting were also conducted [1].

Conclusion

Haemophilia represents both an **economic and health burden**, especially **regarding individual health** on an individual patient level. **Initiatives** to counteract this burden **should be clearly identified and given full support**, as this burden is likely to further increase in the future, especially from an economic perspective. Our study may also contribute towards a better global evaluation of haemophilia in the future.

Results

In Belgium, haemophilia resulted in **145 undiscounted and unweighted DALYs in total** (95% credible interval [CrI]=90-122), which represents an **average of 11 DALYs** per incident case with haemophilia during his life, varying according to haemophilia severity (Table 1).

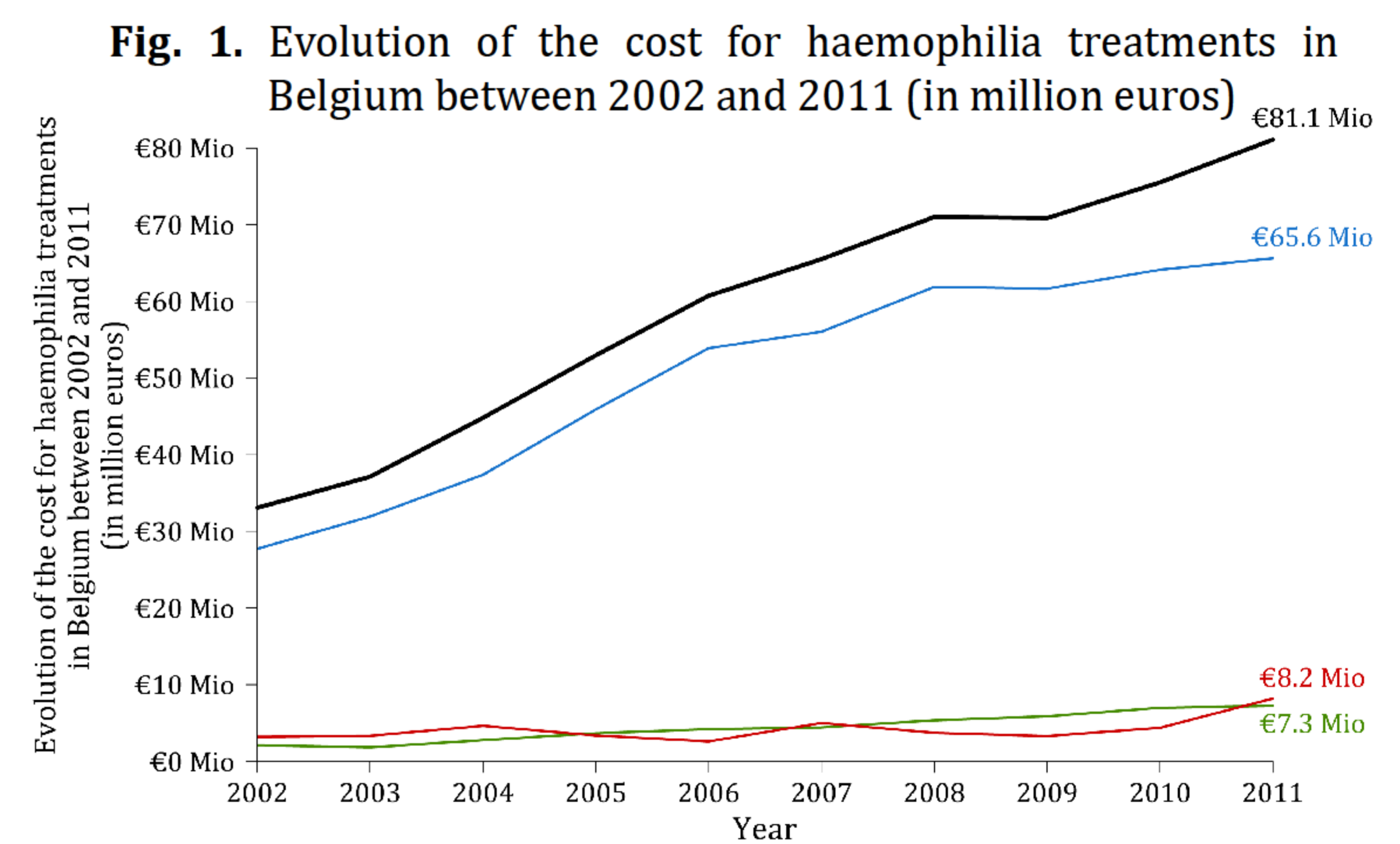
The total lifetime costs were estimated at €97.4 million (95%CrI: €47.1 – €158.1 million) for new incident haemophilia cases born in 2011, with a **mean lifetime cost of €7.8 million** per new incident haemophilia case, 94.3% being direct costs and 5.7% indirect costs. **Clotting factors** accounted for **77.8% of the total** and 82.5% of the direct costs, with €75.4 million for all haemophiliacs. The extensive use of effective prophylactic clotting factor replacement therapies has considerably pushed up treatment-related costs in Belgium (Fig. 1), but has also considerably increased haemophiliacs' quality of life as well as life expectancy.

Tables & Figures

Table 1. Number of estimated new haemophilia cases, overall lifetime haemophilia burden and lifetime haemophilia burden per case per haemophilia severity in 2011 in Belgium

	Estimated number of new cases in 2011 (95% CrI)	DALY (95% CrI)	DALY per case (95% CrI)
Haemophilia (total)	14 (7-22)	145 (90-222)	11 (8-15)
Severe	6 (3-10)	98 (43-175)	17 (13-20)
Moderate	3 (1-5)	29 (27-31)	12 (5-25)
Mild	5 (2-8)	18 (17-20)	4 (2-9)

95%CrI: 95% Credible interval; DALY: Disability-adjusted life year



Legend: — Total cost of haemophilia treatments
— Cost of haemophilia A treatments (coagulation factor VIII)
— Cost of haemophilia B treatments (coagulation factor IX and nonacog alfa)
— Cost of treatments for inhibitors (Factor VIII inhibitor bypassing activity and coagulation factor VIIa)

Reference

1. Henrard S, Devleesschauwer B, Beutels P, Callens M, De Smet F, Hermans C, Speybroeck N. The health and economic burden of haemophilia in Belgium: a rare, expensive and challenging disease. *Orphanet J Rare Dis.* 2014;**9**:39

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