

RARE DISEASES AND THE COST FOR SOCIAL SECURITY SYSTEM: ESTIMATING THE SOCIO-ECONOMIC BURDEN IN ITALY

Claudia Nardone¹, Simone Gazzillo¹, Raffaele Migliorini², Marco Aurilio Trabucco², Francesco S Mennini^{1,3}

¹Economic Evaluation and HTA (EEHTA) – CEIS, University of Rome “Tor Vergata”, Rome, Italy. ²Office of Medical Forensic Coordination, Italian National Social Security Institute (INPS), Rome, Italy. ³Institute of Leadership and Management in Health - Kingston University London, London, UK.

BACKGROUND

Rare diseases imply a significant challenge for health systems because of the risk of not responding to patients’ needs and of not guaranteeing equal access to treatment. Furthermore they imply great clinical and economic burden, also from the social perspective [1]. Cost evidence on rare diseases appears to be very scarce, but when available, they have been found to be a significant economic burden [2].

OBJECTIVES

The aim of the study was to estimate social welfare costs related to social security allowances provided by Italian law and financed by public expenditure, for patients affected by a rare disease. A group of rare diseases was analyzed, including Rare Cancers, such as Chronic Myeloid Leukemia, Rare diseases of the nervous system, e.g. Amyotrophic Lateral Sclerosis and Duchenne Muscular Dystrophy, Rare Endocrine and Metabolic Disease, such as Cystic Fibrosis, and Congenital Anomalies. All diseases considered are listed in Table 1.

METHODS

The analysis focused on two groups of disability allowances, for those who have an injury, physical or mental disability: i) Social Security benefits, reserved to employees, which include Disability Benefits (for people with reduced workability), and Incapacity Pensions (for people without workability); ii) Social Assistance benefits, for people that are substantially restricted in undertaking actions that would otherwise be suitable for their age, experience and qualifications. The national database of disability insurance awards was analyzed considering the period between 2009 and 2015, and the number of beneficiaries and disability costs due to rare diseases were estimated through a probabilistic model with a Monte Carlo simulation.

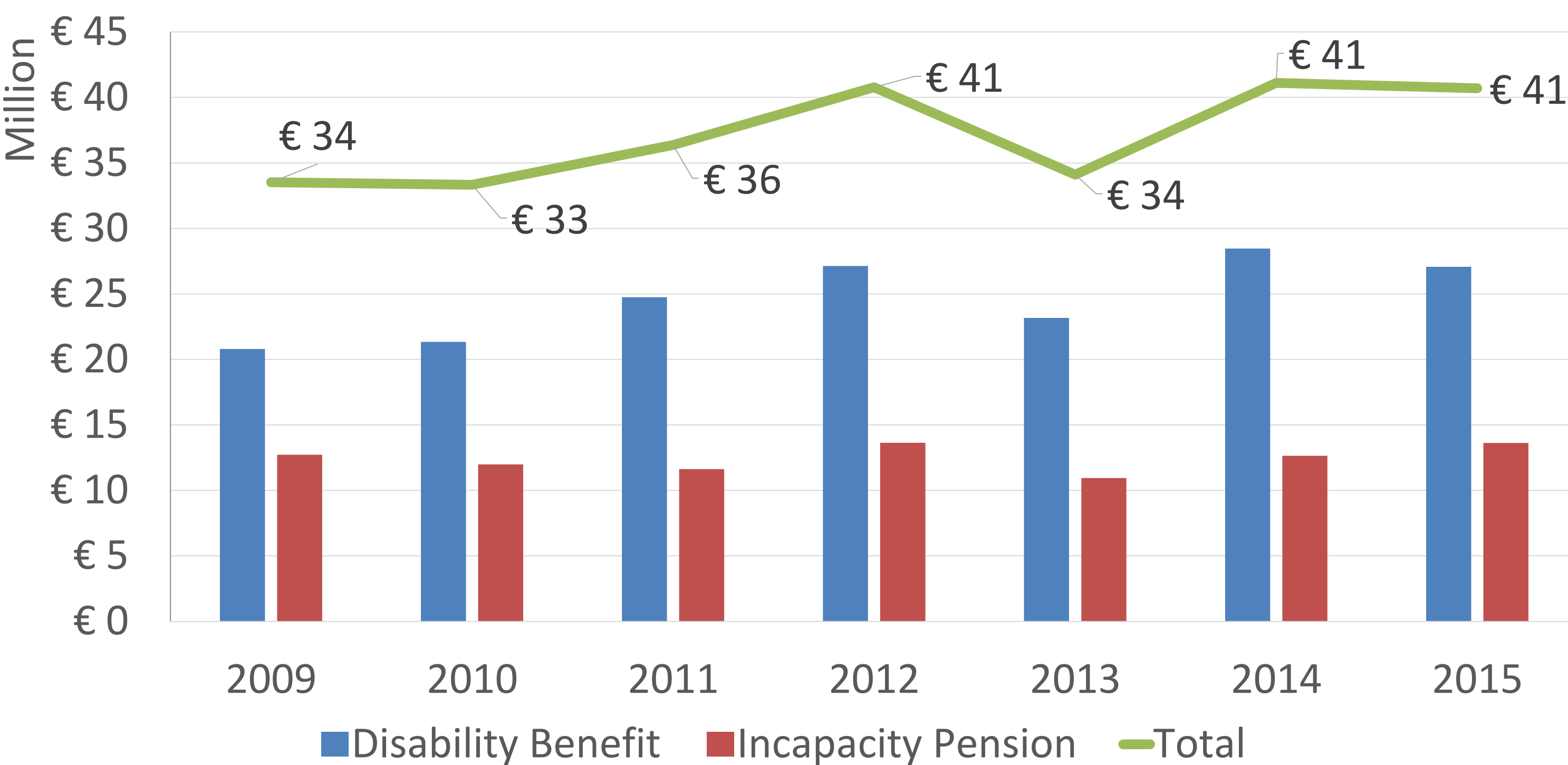
Table 1: List of diseases considered.

Pathological Group	Disease	ICD9 CM code
Neoplasms	Chronic Myeloid Leukemia	205.1
	Neurofibromatosis	237.7
Endocrine and metabolic diseases	Cystic Fibrosis	277.0
	Cushing Syndrome	255.0
	Phenylketonuria	270.1
	Amyotrophic Lateral Sclerosis	335.20
Diseases of the nervous system	Huntington's Chorea	333.4
	Myasthenia gravis	358.0
	Duchenne Muscular Dystrophy	359.1
	Optic Neuromyelitis	341.0
	Narcolepsy	347
Diseases of the musculoskeletal system and connective tissue	Scleroderma	701.1
	Sjögren Syndrome	710.2
	Klinefelter Syndrome	758.7
Congenital anomalies	Ehlers-Danlos Syndrome	756.83
	Fragile X Syndrome	759.83

RESULTS

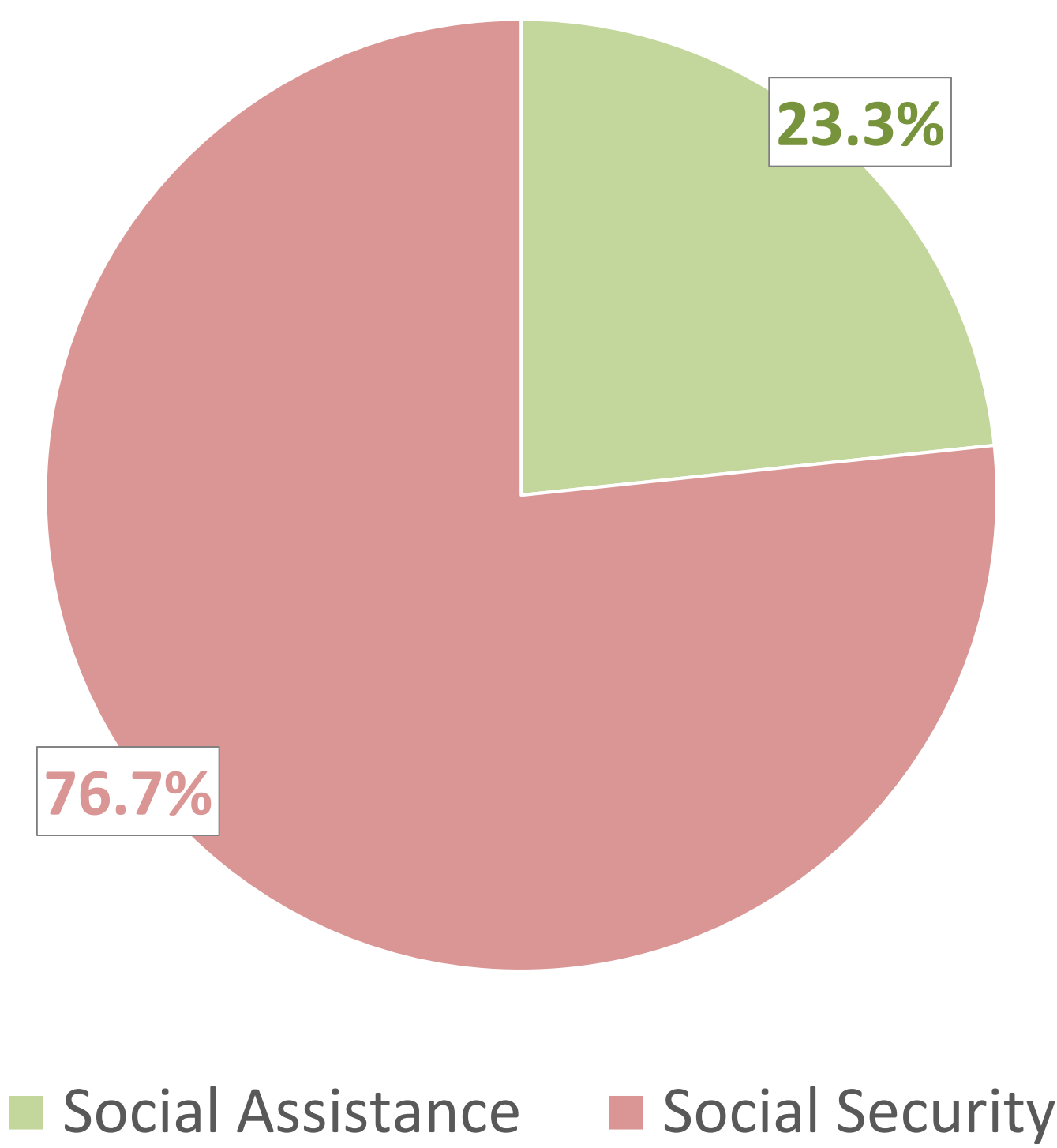
Considering Social Security benefits, the model estimated an annual average of 3,910 beneficiaries affected by one of the Rare Diseases considered: 75% of them have reduced workability, while 25% are completely unable to work. The estimated average annual expenditure for these benefits is equal to € 37 million, that means € € 9,500 for each beneficiary. Figure 1 shows the total social security expenditure for each year considered (2009-2015) per type of benefit (Disability Benefit and Incapacity Pension).

Figure 1: Social Security Expenditure per type of benefit



Social Assistance benefits amounted to 2,836 per year, and an annual expenditure of over € 13 million was detected. Overall, annual average expenditure of € 50.5 million for both types of allowances was estimated, and this means around € 14,200 for each beneficiary affected by one of the rare diseases considered. Figure 2 shows percentage distribution among these two kinds of indirect costs.

Figure 2: Percentage distribution of total social economic burden



CONCLUSION

This study is the first attempt to estimate the overall social costs induced by Rare Diseases in Italy. Results showed a significative and increasing burden for the Italian Social Security System caused by Rare diseases.

REFERENCES

[1] Cannizzo S, et al. (2018). Rare diseases under different levels of economic analysis: current activities, challenges and perspectives. RMD Open; 4:e000794. doi:10.1136/rmdopen-2018-000794

[2] Angelis A et al. (2014). Socio-economic burden of rare diseases: a systematic review of cost of illness evidence. Health Policy, online. pp. 1-44. ISSN 0168-8510 (In Press)

[3]INPS, Banche Dati e Bilanci – Osservatori Statistici: <http://www.inps.it/portale/default.aspx?slD=%3b0%3b6840%3b&lastMenu=6840&iMenu=12&iNodo=6840&p4=2>