Rare Diseases in Spain: a nationwide registry-based mortality study

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AIM

The aim of this study is to assess 15-years mortality trends of Rare Diseases (RD) in Spain.

METHODS

Mortality statistics from Spanish National Statistics Institute provide population-based data. Deaths due to RD were extracted from 15 official annual databases (1999-2013).

Only those ICD-10 codes considered as RD by SpainRDR experts were included in this study. Annual sex- and age-specific adjusted mortality rates per 100,000 inhabitants were calculated and time trends were performed by joinpoint regression analysis.

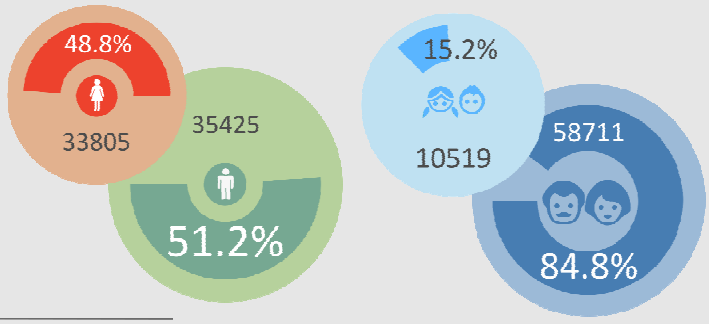
RESULTS

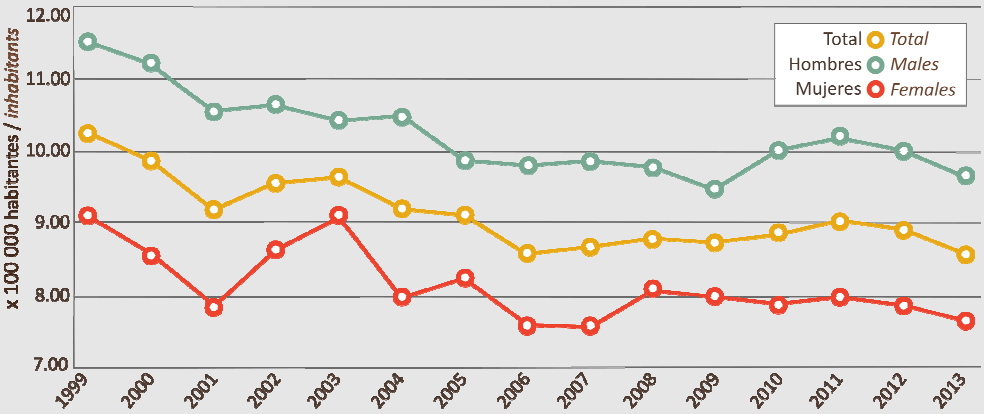
From 1999 to 2013, there has been a **global -0.95% decline in the annual age-adjusted death rates due to RD in Spain**.

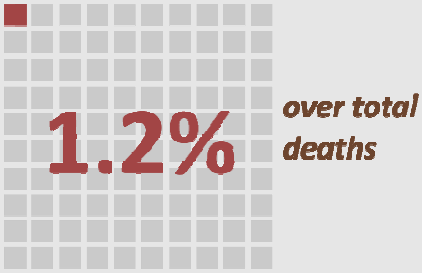
Decrease trends were also observed in the following subgroups of RD: blood and blood-forming organs and certain rare disorders involving the immune mechanism (-2.06%, p<0.001), circulatory system (-3.90%, p<0.01), and congenital malformations, deformations and chromosomal abnormalities (-5.39%, p<0.01).

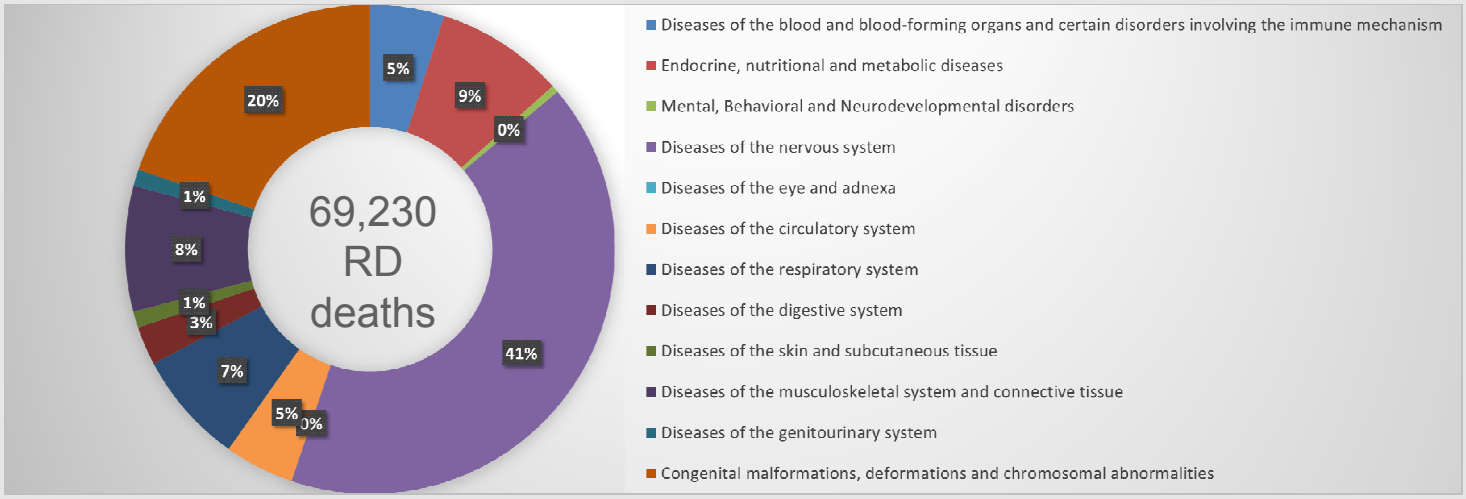
Increase trends of annual age-adjusted death rates were detected for RD of the nervous system (1.85%, p<0.01), RD of the respiratory system (2.39%, p<0.01), RD of the digestive system (1.83%, p<0.05) and those RD affecting the genitourinary system (9.38% p<0.05).

Other RD groups have not showed any significant change in this period.









CONCLUSIONS

Official mortality statistics share criteria for analyzing uniform and robust time series, which is useful for studying low-prevalence diseases.

Assessed RD mortality trends are valuable information for the health authorities in Spain.

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