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THE ECONOMIC BURDEN ON FAMILIES OF CHILDREN WITH TYPE 1 SPINAL MUSCULAR ATROPHY IN BRAZIL: a cross-sectional study

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BACKGROUND

Spinal muscular atrophy (SMA) is a rare, progressive neuromuscular disease that severely impacts patients and their families. Although Brazil provides subsidies for high-cost therapies, families caring for children with type I SMA still face substantial financial hardship. This study aims to estimate the household-level economic burden of SMA in Brazil, highlighting the hidden and catastrophic costs borne by families.

METHODS

We conducted a cross-sectional study with face-to-face interviews administered by trained healthcare professionals using a structured instrument. Data collection included caregivers' intangible and indirect costs, household direct medical costs, and direct non-medical costs. Comparative analyses employed the Student's t-test and Kruskal-Wallis test for continuous variables, and the chi-square test for categorical variables. All costs were converted to PPP-USD, and analyses were performed in R.

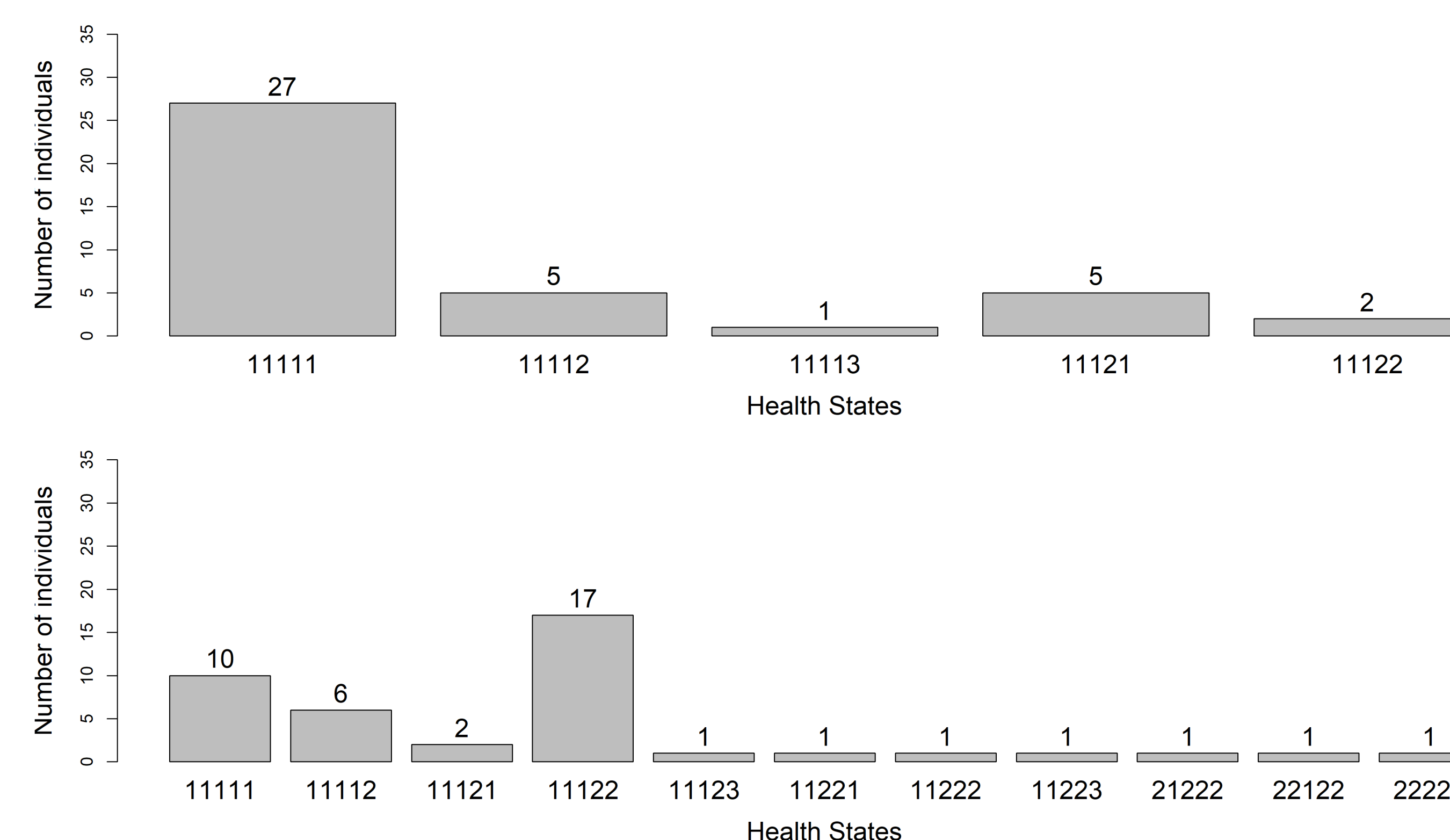
RESULTS

A total of 43 patients from 42 households were included (Figure 1). Utility estimates indicate a loss of quality of life for caregivers after the birth of the child (0.957 vs. 0.846, $p < 0.001$, Figure 2). The difference in utilities generated an average cost of \$3,863.88 ($s = \$4,204.91$) in two years. The average monthly household income was \$2,412.97 ($s = \$3,718.65$) before the birth of the child and \$2,056.66 ($s = \$3,175.78$) after.

Figure 1. Spatial disposition of the patients in the sample.

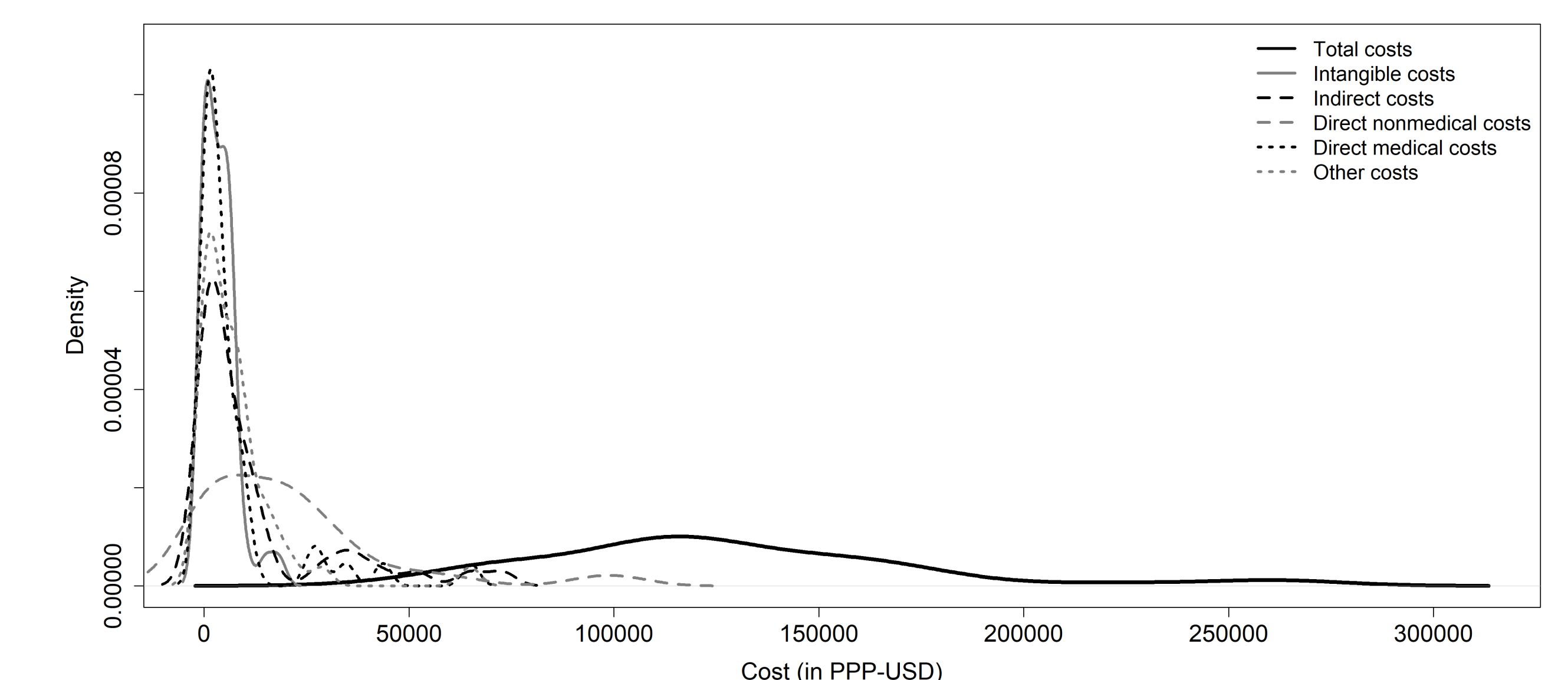


Figure 2. Distribution of caregiver health states.



This difference amounts to a two-year estimate of \$8,551.47. The two-year cost of informal childcare was estimated at \$81,552.85 ($s = \$29,404.40$). The direct non-medical costs amounted to \$20,773.88 in the two-year period. The total cost for the families amounted to an average of \$127,681.6 ($s = \$47,111.19$, Figure 3).

Figure 3. Kernel density plot of total costs in PPP-USD.



CONCLUSIONS

SMA imposes a catastrophic and multidimensional economic burden on families, driven primarily by non-medical and indirect costs. These findings underscore the urgent need for comprehensive support policies that go beyond subsidizing medicines to protect families from financial devastation.

SUPPORT

