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Health literacy, quality of life and burden of informal caregivers in Portugal

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Background:

The process of informal caregiving may have significant impacts on physical, psychological, social and economic conditions of informal caregivers. Worldwide lower levels of health literacy are associated with worse informal care, reduced quality of life and higher burden of informal caregivers. The aim of this study is to assess the correlation between health literacy score (HL), quality of life (QoL) and informal caregiver burden in Portugal.

Methods:

A cross-sectional study was conducted through an online survey directed to informal caregivers. Three validated scales were applied in Portuguese versions: a) European Health Literacy Survey (HLS-EU-PT-Q16); b) European Quality of Life Questionnaire (EQ-5D-5L), c) Modified Caregiver Strain Index (M-CSI). Overall statistical analysis and the Pearson's correlation test at 5% significance level were performed in SPSS[®].

Results:

In total, 760 informal caregivers were surveyed, mean age 57 years (± 9.9), 92.5% female, 62.6% married or living with a partner, 41.5% at least university level, 44.4% works full or part-time. Regarding the process of care, 78.9% takes care of one person, 85.2% have been caring for more than 1 year, 54.3% feel that are not supported at all, and 20.3% do not feel competent to care. The mean HL score of informal caregiver (n = 673) was 31.9 (+7.8), QoL (n = 733) was 0.8 (+0.2), and burden (n = 760) was 14.8 (+5.3). HL Score is directly correlated with QoL ($r = 0.215$; $p < 0.001$) and inversely correlated with informal caregiver burden ($r = -0.150$; $p < 0.001$).

Conclusions:

A higher health literacy score is associated with better quality

of life and lower informal caregiver burden. Improving health literacy may be strategic to promote health conditions and quality of life and care for both the informal caregiver and the person being cared for.

Key messages:

- A higher health literacy score is associated with better quality of life and lower informal caregiver burden.
- It is crucial to invest on the definition of an integrated strategy, between Health and Social Security, to provide better health conditions to informal caregivers.