

Oral presentation

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Two years post-stroke, Luxembourgish informal caregivers' life satisfaction and their couple and family repercussions.

Abstract

Aims (253/300 characters). This study aims to improve our understanding of the changes in the couple and family lives of stroke survivors' caregivers and to analyse the relationships between the Caregivers' Life Satisfaction (CLS) and the social and emotional repercussions of the caregiving role, two years after this event.

Background (900/900 characters). Life satisfaction, optimism about the future, happiness and other subjective well-being aspects have attracted the European policymakers, leading to the Eurofund to introduce a "life satisfaction" dimension in the European Quality of Life Surveys (EQLS). The general subjective appraisal of one's life is now an indicator next to objective measures of economic performance, such as GDP. How is life satisfaction for the main informal caregivers of stroke-survivors, at the Grand-duchy of Luxembourg (one of the smallest UE country, 502 500 hab. (01/2010), 2600 km²).

Individual and family upheavals stroke-related have a major effect on the survivor's life, and on the close relatives and friends' ones. «*The self-assertion on the harmony of the stroke survivor-caregiver pairs*» is the strategy to approach the issue. The implications of these changes are determined by the partners' trajectory. The CLS is disrupted by stroke, but a lack of information remains on caregivers' needs, mostly on the repercussions on the couple and family relationships and projects.

Methods (588/600 characters). Over twelve months, 62 pairs (among them 51 couples) of stroke survivors (64.4 mean age; majors impairments: sensory 53.2% and memory 38.7%) and their main informal caregivers (62 mean age, 61.7% women) consented to participate at a National Survey. Research assistants interviewed them at home, with a face-to-face questionnaire. Caregivers evaluated, on a four-point scale, a list of repercussions; these assertions were built up from a qualitative exploratory study. The LS ten-point scaled was dichotomised in "low (≤ 7 of 10)" and "high (> 7 of 10) life satisfaction" (LLS vs HLS)". Our research protocol was approved by the National Committee of Research Ethics and the Committee for Data Protection.

Results (874/900 characters). Stroke survivors' LS were lightly inferior than the CLS (mean=8) and no significant differences were observed between their socio-demographic characteristics. Comparing the responses obtained on the couple repercussions, the caregivers with LLS had emphasised the impacts of the care provided to their recipients: «*The stroke was experienced as a drama that our couple has never overcome*» (54.2 LLS vs 17.2% HLS; $p \leq 0.001$); «*I cannot leave anymore the stroke survivor alone for a long time*» (60.7% LLS vs 17.4% HLS; $p = 0.001$); «*The stroke has ended with all the life projects that as a couple we made*» (45.8 LLS vs 11.1% HLS ; $p \leq 0.05$); «*The stroke has brought serious turnovers in my couple*» (57.1 LLS vs 25.9% HLS ; $p \leq 0.05$). Regarding family repercussions, the caregivers with LLS had underlined the impacts of their caregiving role: "The stroke is often a cause of the distance *problems we have with our children*" (23.1% LLS vs 0.0% HLS; $p \leq 0.01$), and «*The stroke has brought serious turnovers in my family*» (82.8% LLS vs 51.7% HLS; $p \leq 0.05$).

Conclusions (299/300 characters). CLS and survivors LS were close. Inequalities regarding CLS were identified. Evaluating repercussions on CLS is needed in enabling stroke survivors to live at home. Long-term informal care sustainability has been overlooked; innovative accompaniment and counselling are developed to follow Helsingborg Declaration on European Stroke Strategies.

Keywords (Choose Top 3): Experience of Health and Illness, Health Care Organization, Health Care Work