

Title: Trajectory and determinants of the caregiving burden of family caregivers of terminally ill cancer patients in Taiwan.

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Aim:

The effect of caring for a dying cancer patient on caregiving burden has been explored primarily with small sample sizes or short-term follow-ups in western countries, but has not yet been investigated in Taiwan. The purposes of this study were identify the trajectory of the caregiving burden of family caregivers (FCs) of terminally ill cancer patients in Taiwan, and investigate the determinants of the caregiving burden of FCs, in a large sample and with longer follow-ups.

Design and methods

This longitudinal survey study was conducted with 226 FCs who had a relative with terminal stage cancer. The Caregiver Reaction Assessment (CRA), the Symptom Distress Scale (SDS), the Senses of Coherence (SOC), the MOS Social Support Survey (MOS-SSS) were administered during follow-up until the time of patients' death. This study analyzed the proximity in time to the patient's death as a continuous variable to assess its association with the CRA scores, using a generalized estimation equation (GEE).

Results

The study showed that the caregiving burden did not increase significantly as the patient's death approached. The results indicated that this deterioration of a caregiving burden reflects the patient's increasing symptom distress ( $\beta=0.11, p=0.05$ ), high intensity of total assistance in caregiving ( $\beta=0.44, p=0.0001$ ), the gradual loss of confidence in caregiving ( $\beta=0.60, p=0.003$ ), the financial difficulty of FCs ( $\beta=3.81, p=0.03$ ), lower social support ( $\beta=0.16, p<0.001$ ) and weak SOC ( $\beta=0.13, p=0.01$ ).

Conclusion

Caregiving burden was a non-significant change from the time of the patient's death in Taiwan. This study contributes to the family caregiving literature by using longitudinal data to confirm that the confidence in caregiving, social support, and psychological recourse are important predictors of caregiving burden.