

Journal Club

Caring for a Loved One with Advanced Cancer

Determinants of Psychological Distress in Family Caregivers

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Abstract: **BACKGROUND:** Family caregivers caring for a patient with terminal cancer may experience significant psychological distress. **OBJECTIVE:** The purpose of this study was to determine the extent to which the family caregivers' psychological distress is influenced by the patients' performance status while taking into account individual characteristics of caregivers and their unmet needs. **METHODS:** Two hundred twelve family caregivers were assigned to three cohorts according to the patient's performance status, as measured by the Eastern Collaborative Oncology Group Functional Scale (ECOGS). Interview information was collected on the services and care provided, as well as on the caregivers' characteristics and level of psychological distress. **RESULTS:** Family caregivers' psychosocial distress is strongly associated with the patients' terminal disease progress and declined functioning. The level of psychological distress varies from 25.2 to 33.5 ($p = 0.0008$) between the groups. Moreover, the percentage of caregivers with a high level of psychological distress varies from 41% to 62%, while this percentage is estimated at 19.2% in general population. A high distress index was significantly associated with the caregiver's burden, the patient's young age, the patient's symptoms, the caregiver's young age and gender, a poor perception of his/her health and dissatisfaction with emotional and tangible support. **CONCLUSIONS:** Family caregivers of patients in the advanced stages of cancer experience a high level of psychological distress, which increases significantly as the patient loses autonomy. Health care policies and programs need to be revisited in order to take the reality of these patients and their families into account.

Clinical Question

Which factors (patient and caregiver) influence the psychological distress of family caregivers of patients with advanced cancer?

Summary

A prospective, cross-sectional study of primary caregivers of patients with advanced cancer was performed to determine the extent to which family caregiver's psychological distress is influenced by the performance status of the patient.

212 main caregivers were recruited and interviewed using standardized interview assessments of distress. They were divided into 3 cohorts based on the performance status of the patients (ECOGPS):

1. patient confined to a bed or chair for <50% of waking hours (grade 2)
2. patient confined to a bed or chair for >50% but <100% of waking hours (grade 3)
3. completely bedridden patient (grade 4)

Family caregivers' psychosocial distress is strongly associated with the patients' terminal disease progress and declined functioning. The level of psychological distress varies from 25.2 to 33.5 ($p = 0.0008$) between the groups. Moreover, the percentage of caregivers with a high level of psychological distress varies from 41% to 62%, while this percentage is estimated at 19.2% in general population. A high distress index was significantly associated with the caregiver's burden, the patient's young age, the patient's symptoms, the caregiver's young age and gender, a poor perception of his/her health and dissatisfaction with emotional and tangible support.

Strengths

- Prospective study using standardized interview assessments
- Provides an objective assessment of the difficulty of care in the home setting
- Showed a strong association with the patient's level of functioning
- Highlights that psychological distress is significant, even in young caregivers

Weaknesses

- Possible selection bias (avoidance of solicitation of caregivers for fear of adding to their burden) – underrepresentation of caregivers with high levels of distress
- One time point – although some caregivers participated in multiple interviews, the possible change in level of distress was not specifically examined
- Relatively homogeneous population (Quebec francophone), unable to consider ethnic and cultural influences
- Level of income and financial resources not assessed

Relevance to Palliative Care

As the main caregivers of our patient population outside the hospital setting, these people play a large role in ensuring a strong quality of life at the end of a patient's life.

Recognizing the caregiver's level of psychological distress and appropriately supporting them will benefit both the patient's well-being, and the caregiver's well-being before and after the patient dies.