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68 – Relevance and Distress of Caregivers in Management of Chronic Patients

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Population's progressive ageing in most of developed Countries raises several questions about care and assistance to elderly patients, often at high risk for multiple diseases and for loss of self-reliance. In this context we find the caregiver, the person who cares for the patient every day.

Caregiver's time dedicated to this activity is comparable to a real and actual job, and hours spent on it increase as patient's conditions worsen, becoming a full-time occupation. The consequences of this task are not to be underrated by the family doctor, mainly because these persons are at higher risk to impair their psychophysical health with respect to the general population.

Since several years, with increasing frequency, we meet the figure of the helper caregiver (watchman), usually an immigrant (male/female) looking after the patient under the control of a member of the family.

A person can become a caregiver by choice or family appointment, when personal or relational history give no other possibilities.

My aim here is:

1. To draw and describe the subjective burden (over)loading relatives and third persons that look after a patient needing continuous care and attention;
2. To understand f and how the subjective burden experienced by the caregiver is affected by caregivers' characteristics (psychological-relational characteristics) and by support resources at their disposal;
3. To assess family doctor's role as a support figure;
4. Starting from the profile so characterized, to suggest some Intervention hypothesis aimed to optimize the support provided to the families by Health and Social Services network

Three very frequent problems to which family doctor ought to pay special attention are cognitive impairment, falls and postural unsteadiness, and urine incontinence.

In the world, 2,4% of disabled prove to be affected by dementia pathology, but taking into consideration the ones over 65 the percentage arises to 8,7%.

Care is supplied mainly by women, with family and sons/daughters, housing the patient at home. 73% of caregivers is female and the percentage of women increases with increasing severity of patient's illness (81% of seriously ill patients' caregivers are women).

Intergenerational and intragenerational solidarity plays an essential role in the care network, since patients' sons, and especially daughters, are the most active subjects. Actually, 49% of caregivers are patients' sons/daughters, 34% are patients' partner/spouse/husband.

With respect to general population, these subjects are at higher risk to impair their psychophysical health. Chronic patient's suffering progression (meaning the sum of psychic, existential and spiritual distress, and of somatic symptoms) directly affects emotional and relational experiences of caregivers in the family system.

44% of caregivers consider the relationship with the patient fairly difficult to manage. Illness costs impact on family budget, 31% had to change job. In most critical moments, caregivers need support, more leisure time, temporary substitution in patient assistance and possibility of temporary admission in hospital or other institutions.

51% find their life rhythm upset and experience important consequences on their physical conditions, as sleep alteration, weight loss due to reduction of appetite, fatigue, sudden headaches. 56% show the need to give expression to their own emotions and the wish to have at hand someone willing to listen, particularly other family members and health workers. 40% emphasized that commitment to the ill relative impaired their social relationship, and 36% noted changes also in their own private life.

Caregivers experience similar, complementary and/or defensive emotions in reply to the suffering of the patient they care for, through mechanisms as cognitive empathy, mimicry and conditioned learning. Risk factors for caregiver's psychophysical well-being are social isolation, poor knowledge of disease, reduced willingness in social relationships, guilt feelings, stress and fatigue in the relationship, poor coping skill and high emotionality showed, that expose to burnout risk.

A clear majority of caregivers receive medical help by the family doctor, alone or in association with psychiatrists, physiotherapists and nurses, but family doctors are the first ones also for psychological help and are clearly the point of reference.

Take Home Message

- Caregivers' service burden is heavy, with a need to voice their own emotions and a need to have someone at hand willing to listen (psychologists are required)
- Caregivers' distress is high also in common and general contexts, not necessarily specific ones, and the female gender is more -(over)loaded with tasks
- The family doctor is the professional figure of reference, playing the role of health educator, a real and actual counsellor. Then, he has to ensure communication to caregivers both as information source and as psychological support, making his practice become a welcoming place, inducing patient's relatives to leave the story of their caregiver work in good hands
- It is necessary to make available to all patient affected by chronic degenerative diseases a series of social services already existing, like relief admission into hospital or other institutes and day centres, and give the caregivers the chance to cope with their feeling of failure, their wish to give expression to own emotions, their physical distress, providing individual psychological support, often required by interviewed caregivers, as short counselling.
- Interventions aimed to the real and actual caregiver's formation are needed, with special attention in helping to reduce patient's suffering and to cope with the aspects of suffering that are not manageable

Original Abstract

<http://www.woncaeurope.org/content/352-caregiver-burden-spouse-and-adult-children-patients-alzheimer%E2%80%99s-disease-%E2%80%93-baseline>

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