Importance of informal caregivers

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Our rapidly changing world

Longer life expectancy

Increase in the total number of elderly individuals

But also a raise on the level of dependency in this age group.

Dependency leads to a physical decline that brings a need for psychosocial and health care services,

Coincidental reduced income in retirement and a lack of adaptability to new situations that put the elderly person at a disadvantage

(Organization for Economic Cooperation and Development [OECD], 2009).
Universal Ageing Process

- morbidity, changes and great challenges to health and social care systems
- Turkish Health System has been highly segmented since 2010 causing large disparities in access and a lack of response to health needs of older adults.
- Social security institutions provide health and social services to those with a formal employment status, and their eligibility for pensions and retirement benefits will depend on past participation in formal employment.
- In such countries, the care of older individuals is often family focused and unpaid, and most caregivers are female.

Support Services

1-formal professional support services,
2-informal support; provided by individuals, agencies, and networks

- family members are the main source. The person who takes the major responsibility for this care is defined as the primary caregiver for the dependent patient/disabled.
- a clear reason to remain in the home community,
- assist with basic and functional needs of daily living during most of the day,
- without economic compensation for this task !!!
Informal caregivers play an important role in the realisation of an effective home care.
THE IMPACT OF CAREGIVING

As a society, it’s time we value the important work of family caregivers and understand their enormous impact.

Profile of Caregivers

- **66m** Total Caregivers
- **470b*** Total estimated value of unpaid caregiver services (in 2011)

Shape of the Elder Population

- **11.3%** of total population in 1980
- **20.1%** of total population in 2050
- **Up 77.8%**

Time and Impact

- **20.4** Average hours per week spent caregiving
- **2/3s** of caregivers believe that web-based and mobile tech would be helpful to them
- **$3t** Estimated lost wages, benefits, retirement funding
- **39.3** Average hours per week spent giving care if living with care recipient (includes 20.4)

If you have specific questions, contact us at info@seniorlink.com
Excessive Stress = Caregiver Burden

Which has both objective and subjective components.

*The objective components*; the demands, to which the caregiver is exposed because of caring for the dependent person.

*The subjective components*; the way the caregiver perceives the caregiving tasks. His or her emotional response to the experience of caring for a family member.

«various challenges, meeting the care needs of their relative, but also dealing with the demands on their own health, on the family and perhaps also their job situation»
Caring for an older relative can be a stressful experience that can become harmful to the caregiver’s health and wellbeing. BUT among the negative consequences of caregiving, subjective burden is one of the most frequently analyzed. Subjective burden is defined as a caregiver’s state characterized by fatigue, stress, and perception of limited social contact and role adjustment, which comes from a negative appraisal of the caregiving situation, and such as can threaten the physical, psychological, emotional, and functional health of caregivers.

(Pinquart & Sorensen, 2003b).
A study of informal caregivers in primary care context

assessed the existence and causes of caregiver burden, along with the consequences for the patients, and observed that the overwhelmed caregiver has;

• poor social support,
• cares for a severely dependent patient,
• has been filling this role for a long time,

In that study, 66.5% of caregiver burden was due to insufficient social support and variables related to the dependent patient, including age, cognitive status, and degree of dependency.

Management

An inverse relationship has been reported between scores on the Medical Outcomes Study test which evaluates the social support received, and the Zarit test, which measures caregiver burden.

Of all the factors related to caregiver burden, the easiest to modify is social support.

Reinforcing social support reduces caregiver burden and improves quality of life, providing tools that respond more effectively to crises resulting dependent patient’s status.
Intervention to improve social and family support for caregivers of dependent patients: ICIAS study protocol.

- decrease their stress,
- strengthening their psychological well-being
- plan structured external interventions

health care programmes with cerebrovascular accident, dementia, and schizophrenia.

Rosell-Murphy et al. BMC Family Practice 2014, 15:53
http://www.biomedcentral.com/1471-2296/15/53
The association between positive–negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study

What are the key findings?

- Links between negative caregiver reactions to dementia and informal caregiver. Healthcare-related outcomes tend to be stronger in home care than in nursing homes.
- Both informal caregivers’ health issues and disrupted schedules are associated with negative aspects of caregiver reactions.
- Nursing involvement is essential to assess and support informal caregivers in avoiding negative healthcare outcomes in both themselves and people with dementia.
At the end of such programs;

Caring for someone with dementia may have implications for the caregiver’s own health and for the care recipient. These consequences could be associated with caregivers’ reactions to the process of care.
Quality of life of the informal caregiver

When the emotional involvement is very intense, frequent, or longlasting, the caregiver’s health and behaviour may be affected.

The evaluation of psychological well-being, a central component of health-related quality of life (HRQL), is also considered important.

Some studies have suggested that this indicator can be improved even when caregivers are excessively stressed, and health and well-being of caregivers must be complemented with assessments of quality of life or related aspects.

Rosell-Murphy et al. Intervention to improve social and family support for caregivers of dependent patients: ICIAS study protocol. BMC Family Practice 2014, 15:53.
Family caregivers, report lower health-related quality of life

These caring tasks influence caregivers physically, emotionally, and socially.

- emotionally, they have to deal with, for example, fear or loss.
- lack sleep and feel tired and exhausted, may suffer from anxiety and depression
- dyspnoea, fatigue and pain as the most highly reported symptoms,
- they link appetite with the wellbeing of the patient.

However, patient’s loss of appetite had no influence at all on the development of caregivers’ sense of burden.
Create a risk profile in primary family caregivers

Individuals who are at risk are characterized as;

- young,
- female,
- offspring who live with the care recipient,
- care for a care recipient with behavioral problems, are unsatisfied with the social support received.

Nurses can use this risk profile for the early prevention of and intervention for subjective burden, thereby reducing the negative emotional effects of caregiving.
Interventions focussed only on information, support groups, or management of behavioural disorders have not proven their effectiveness.

Psychosocial interventions that address multiple dimensions (information about the disease, organization of care needs, practical advice, skill-building for care management, decision making) are most indicated.

The most successful models of intervention have involved long-term support for informal caregivers over a period of years. In this regard, other family members are among the caregiver’s most accessible resources for ongoing support over time.
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Caregiver Survival Tips

1. Plan ahead
2. Learn about available resources
3. Take one day at a time
4. Develop contingency plans
5. Accept help
6. Make YOUR health a priority
7. Get enough rest and eat properly
8. Make time for leisure
9. Be good to yourself!
10. Share your feelings with others

Personalized care in daily practice
Personalized and multi-intervention

- incorporated individual counselling, self-help groups, family therapy, caregiver training, and technological support;
- also personalized to meet the specific needs of the caregiver.

有效 in improving caregiver health and delaying the institutionalization of the dependent patient
Protective factors for subjective burden

perceived social support and balanced reciprocity

Rafael del-Pino-Casado et al.  
Correlation between patient quality of life in palliative care and burden of their family caregivers: a prospective observational cohort study.
Krug et al. BMC Palliative Care (2016) 15:4