

THE HIDDEN COST OF CAREGIVING

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July 21, 2000 (Reviewed: December 11, 2002)

It is generally recognized that caring for an elderly person with disabilities is, or can be, extremely stressful. The result is caregiver burnout, which may lead to actual physical or mental illness. Today, most caregivers are middle-aged grownup children or older spouses, caring for a parent or a spouse with disabilities. A recent study has examined the death rates for spousal caregivers, to see if they are at increased risk because of their undertaking.

Four communities in the USA supplied participants to this study. A caregiver was defined as someone whose spouse had difficulty with at least one of the recognized activities of daily living, or what is called an instrumental activity of daily living, due to physical health problems or mental confusion. A control group was made up of people whose spouses did not have any such disability.

At the time of enrollment, information on health was collected, and the participants were classified according to their health status. They were all asked to answer the question "how much of a mental or emotional strain is it on you to either provide the help directly, or to arrange for help to be provided for this activity?" Their responses divided them into three groups (1) those not helping a disabled spouse (2) those helping a disabled spouse but not experiencing caregiving strain, and (3) those helping a disabled spouse but experiencing caregiving strain. Participants in the study were followed for an average of 4 1/2 years. Information on deaths among participants was obtained from obituaries, medical records, death certificates etc.

There were 392 caregivers and 427 noncaregivers (controls) in the study. They were aged 66 to 96, with an average age of 80. Just over half of them were women. Out of those with spouses requiring care, 80% were providing care themselves, and 56% of these reported having "caregiver strain". A quarter of all caregivers had at least one existing disease at baseline, and another 40% had test results indicating a hidden (or subclinical) disease.

Four years after baseline, 103 (12.5%) of the participants had died. When compared with the control subjects -- i.e. those having spouses without any disability - and after adjustment for possible bias due to existing diseases, the likelihood of dying was 1.4 times greater in those not helping with their disabled spouse, and 1.1 times greater in those helping a disabled spouse but not reporting any strain with this. These results were not large enough to be considered significant. However, in the caregivers who were helping their disabled spouse but reporting strain associated with this activity, the likelihood of dying within 4 years was 1.6 times that of the control group. This was considered a significant increase in the risk of dying. These results showed that being a caregiver and experiencing mental or emotional strain is indeed a risk factor for earlier death. It is probable that this finding would be the same if the study had been conducted in middle-aged children caring for a disabled parent. The consequences are obvious. Firstly, caregivers who are suffering strain must be identified - this may not be easy (see

How To Spot Caregiver Burnout). Then, help for the caregiver must be provided. Health care professionals are in the best position to ensure that such assistance is made available (see Help for Caregivers). In this way it may be possible to improve the outlook for the caregiver, who is indeed giving much, but is at increased risk to her or his own existence.

En partenariat avec Health and Age

CAREGIVING AS A RISK FACTOR FOR MORTALITY R. SCHULZ, SR. BEACH, THE CAREGIVER HEALTH EFFECTS STUDY. JAMA, 1999, VOL. 282, PP. 2215--2219