

Quality of Life in Caregivers of Persons With ALS: An Important But Infrequently Discussed Issue

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As many of you know, the Hershey Medical Center ALS team has had a longstanding interest in the issue of quality of life. In the last newsletter, I wrote about our studies involving quality of life in persons with ALS. However, as many of you know, ALS is a disease which has a profound impact on not only the individual who carries that diagnosis, but on many persons who are close to the affected individual. Within any household, there is usually one person who acts as the primary caregiver for the person with ALS. This is most often the spouse or an adult child, but may be another family member or a close friend. Being a caregiver for a person with ALS can be rewarding, but also may be exhausting, both physically and mentally! It may require virtually all of one's time day after day, for months or years, and can lead to physical injuries, depression, resentment, and guilt. Some caregivers appear to shoulder this enormous responsibility with relative ease, while others appear to struggle more.

Just as persons with ALS may have varying opinions of their quality of life, so do caregivers of those persons. We believe that if we can identify those factors which influence caregivers' opinions of their quality of life, we can try to help in such a way as to improve quality of life for the caregivers. This should lead to a better quality of life for the person with ALS as well, since a contented, optimistic caregiver should be capable of providing a more positive, hopeful, encouraging, and enjoyable environment for a person with ALS than a caregiver who is depressed, anxious, or sad.

Based on this belief, we have been conducting a study of quality of life in ALS caregivers. So far, 67 caregivers have participated in our study, which involves filling out several questionnaires in our ALS clinic. Interestingly, the level of care required by the person with ALS (as determined by their degree of physical impairment) did not predict the quality of life or the psychological health of the caregiver. In other words, those caring for the weakest, most dependent persons with ALS were not necessarily those caregivers most likely to see themselves as having the poorest quality of life. Specifically, we have found that a positive relationship between the caregiver and the person with ALS and good problem-solving skills on the part of the caregiver

both are important factors in predicting a good quality of life for the caregiver. Such caregivers often find caregiving for persons with ALS emotionally rewarding. In contrast, caregivers who had a less satisfactory relationship with the person with ALS and those who had a negative approach to problem-solving (viewing problems as threats rather than challenges) were more likely to experience such negative emotions as anxiety, depression, and hostility.

We have presented these results at the Association for Advancement of Behavior Therapy and the American Academy of Neurology in an attempt to educate others about this. We are continuing to collect information from our caregivers in an attempt to understand other factors which may contribute to their quality of life, and to see how quality of life for caregivers changes as the disease progresses. Eventually, we hope to use this information to improve the quality of life for ALS caregivers.

I am indebted to Virginia Murphy-Reiley, Dr. Barbara Bremer, Dr. Stephanie Felgoise, our nurse Susan Walsh, and several students for all their work on this study. Most importantly, I am deeply grateful to the ALS caregivers, who took the time to participate in this study which we hope will provide us with the insight to be better providers of care both to our patients and to their caregivers.