

The forgotten “patient” – why the relative needs more of our attention. An explorative interview study with ALS patients and their primary caregivers

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Background and questions

Medicine has for a long time notoriously neglected the family of the patient. More recently, clinical medicine has discovered the relatives as a “resource” of supporting the patient, rather than as individuals who are suffering themselves. In this study 30 ALS patients and their primary caregivers participate in an explorative interview, which focuses:

1. on the formation process, development and application of end-of-life decisions in the situation of a life-threatening disease;
2. on questions regarding religious and/or spiritual attitude, primarily on the patients side.

How and why do certain decisions evolve in a patient? Are they paralleled by their primary caregivers? What is the significance of the information given to the patient by health care professionals for the decision-making process?

Method

The quantitative and qualitative interview study includes 30 patients suffering from Amyotrophic Lateral Sclerosis (ALS) as well as their primary caregivers. All participants will be interviewed again no later than 15 months after the first inquiry. The study started in October 2008, completion is scheduled for 2010.

Results

During the course of the interview study it has become clear that health care professionals ought to dedicate more time and care to the primary caregivers of patients suffering from ALS. When asked to evaluate the overall life situation (i.e. quality of life; partnership a.o.) oftentimes the views of the patient and of his/her relative drift apart extensively. The spouse, for example, has to deal with tremendous bureaucratic hurdles such as getting finances for rebuilding the home for disabled. When children are at home, they need particular attention in face of the fatal disease of a parent. Due to the progressive course of the disease the spouse often will not be able to continue to work as he or she used to do, but will have to take care of the patient. Additional to financial problems, which might occur, the loss of social contacts is a common problem.

Conclusion

Caring for the patients’ primary caregivers / spouses is an important task for health care professionals as well as for society at large. The tremendous challenge of living together with a loved one who is suffering from a fatal disease not only creates emotional burdens; rather, dropping out of social networks, facing problems with other family members such as young children and at times suffering financial problems may well lead to severe personal difficulties, even in the healthy relative. Caregivers ought not to forget these “patients” and their suffering.