

Quality of Life: It May Not Be What You Think It Is

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As many of you know from the questionnaires you have been filling out at the Hershey Medical Center ALS Clinic, we continue to be deeply involved in trying to better understand issues surrounding quality of life (QOL). Through the dedication of several health care professionals in our ALS clinic, we are developing a much better understanding of why some persons with ALS consider their QOL to be high, while others believe just the opposite. I have written about QOL issues for our readers in the past, and thought that this would be a good time for an update.

The term "Quality of Life" is one that gets a lot of use. What does it mean, though? If you speak with most individuals who are in good health, they frequently equate good QOL with good physical health. As an extension of that, physical limitations are often seen by those without serious illness as producing a poor QOL. Doctors, nurses, and other health care professionals are not immune to this generalization. In fact, many of the QOL scales used by physicians to assess the welfare of patients in clinical treatment trials are heavily weighted toward physical function, and so inevitably decline as patients weaken. Is it fair, or indeed correct, to conclude that patients experience a poorer QOL as they become weaker? This would mean that QOL for all individuals with ALS would decline over time, since ALS inevitably results in progressive loss of muscle strength!! Yet, I'm sure that many of you would disagree with such a conclusion.

This is not to say that individuals with ALS are inevitably happy with their lot in life, or that they are oblivious to the progression of their disease and the physical limitations associated with it. However, interviews with our patients have taught my colleagues and me that QOL is determined by many factors, and is dependent not only on physical function. In a paper we published in the journal *Neurology*, we began with the assumption that individuals with ALS were their own best judges of those factors which determined their QOL. Based on this, and by conducting interviews with 96 patients with ALS, we found that QOL in these individuals did not correspond to measures of strength and physical function. In other words, individuals with ALS who were weak did not necessarily believe that their QOL was poorer than those who had ALS and were still relatively strong. What factors appeared to influence QOL? 1) Psychological factors such as depression, worry, nervousness, sadness, and view of the future; 2) "existential factors" such as the meaning one sees in one's life, progress toward achieving life's goals,

and the level of control one has over one's life; 3) the support patients receive from family, friends, and other caregivers; 4) spiritual and religious factors. These results were supported in a second study, soon to be published in the same journal. In that study, we followed 60 patients with ALS over a series of visits, and found that as strength and physical function declined in individuals with ALS, those individuals did not necessarily believe that their QOL was declining.

What are our goals? We hope that this information will permit us to help those persons with ALS who see their QOL as poor. What does the future hold? We are currently working to expand this study to other ALS clinics. We are also in the process of studying QOL in caregivers of persons with ALS. As most of you know, ALS has an enormous impact not only on the affected individual, but on family members and other caregivers as well. Until ALS is cured, I believe it is critically important that we look for ways to maximize QOL for persons living with ALS. I am most indebted to our patients for sharing with us their confidential thoughts, hopes, and fears, and thus helping us to appreciate the many factors that go into determining QOL.