

Quality of Life in ALS Revisited

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Zachary Simmons, MD

In ALS Centers such as those certified and supported by the ALS Association, we attempt to maximize quality of life (QOL) by identifying factors which have the greatest positive impact, and by helping people with ALS and their families recognize and benefit from those factors. We know that we cannot (yet) cure ALS, but we believe we can help individuals afflicted with this devastating disease lead lives of higher quality and greater meaning. Those of you who are familiar with our work on QOL in ALS know that it is not dependent on strength or physical function, but derives largely from other factors which include psychological factors, existential factors (meaning and purpose), spirituality/religion, and support from family and friends.

My colleagues and I (Dr. Stephanie Felgoise of the Philadelphia College of Osteopathic Medicine, Dr. Barbara Bremer of Penn State Harrisburg, our ALS research coordinator Beth Stephens, and our ALS nurse Sue Walsh) explored this further when we undertook a study in collaboration with the ALS clinic at the University of Utah. We used an instrument known as the Schedule for the Evaluation of Individual Quality of Life (SEIQoL), which asks individuals to identify those five factors (cues) which are most important in determining their QOL, and to rate the importance of those cues. Of 120 people with ALS who participated in the study, 90% chose family and significant others as one of their 5 cues, while 54% chose hobbies, 56% chose religion, and 39% chose friends. Only 29% identified physical function as one of their cues. Similarly, when asked to rate the importance of each cue on a 1-100 scale, family and significant others was given an average weight of 26, religion 24, and hobbies 15. Physical function was weighted 16 on average. Thus, while physical function clearly plays a role in determining QOL, it is not considered nearly as important as some other factors by most people with ALS.

It has also become clear that the perception of what is important changes over time. Physical function is a much more important component of QOL to those without ALS and to those in the early stages of ALS than it is to those who have lost considerable strength. In *Tuesdays With Morrie*, we are told that as Morrie's illness advanced, he spent time "...listening more to music and watching the leaves change color through his window." As humans, we find meaning in those activities and interactions in which we are able to participate and which give us pleasure. It is logical that these would evolve over time as physical abilities change.

Although the SEIQoL provides much insight into individuals with ALS, it is not a useful instrument for measuring QOL in large groups of individuals, such as those undergoing clinical trials of new treatments. The Food and Drug Administration has mandated that QOL be evaluated in such trials, the logic being that if a new treatment extends lifespan by 6 months, but the individuals taking that treatment are sickened by side effects such as nausea, extreme fatigue, dizziness, or headaches, QOL may decrease, raising questions as to the overall value of the new treatment. To help assess QOL in this context, we developed the ALS-Specific QOL

Questionnaire (ALSSQOL). This was derived from an existing QOL instrument, and augmented by our previous studies on QOL, interviews with our patients, and written input by our patients as to what factors contribute to QOL. We organized a large study involving 342 individuals with ALS at 7 university-based ALS clinics, and identified 6 domains as being important to QOL: 1) negative emotion; 2) interaction with people and the environment; 3) intimacy; 4) religion; 5) physical symptoms; 6) bulbar function. Interestingly, of the 46 items in the questionnaire, only 11 fall into the categories of physical symptoms or bulbar function. The remainder focus on support, religion, and psychological issues.

A Dutch study of over 200 individuals with ALS found that those treated by a multidisciplinary ALS team had better mental health than those not treated by such a team. We are now in the process of creating an on-line version of the ALSSQOL. Working in collaboration with the ALS Association, our goal is to assess QOL in those individuals with ALS in the United States who do not attend multidisciplinary ALS clinics, and to compare this to those who attend such clinics. If we find, as did the Dutch group, that QOL is higher in those individuals who attend such centers, then it is the responsibility of those of us involved in the care of people with ALS to identify ways to bring these services and supports to those who are currently unserved or underserved.

Milhorat has said: “We must ever be mindful that our function as physicians is to cure when we can; if we cannot cure, let us treat if we can; if we cannot treat, let us comfort.” If we substitute the words “ALS centers” for “physicians,” then this quote certainly summarizes our mission, and it is one to which ALS centers and chapters are committed.