Quality of Life: The Role of Religion

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Zachary Simmons, MD

As many of you know, my colleagues and I at Hershey Medical Center continue to be very interested in learning more about issues involving quality of life (QOL) for individuals with ALS and their caregivers. Thanks to our patients and their families, we have learned much, and have been able to publish these results in the journal *Neurology* so that others may learn from our experience. Our first study taught us something which many of you may already know: those who are most physically limited by ALS do not necessarily see themselves as having a low QOL. Instead, QOL depends on a number of other factors, including the following: 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 individuals with ALS receive from family, friends, and other caregivers; 4) spiritual and religious factors. These results were supported in a second study of 60 individuals with ALS over a series of visits, in which we found that as strength and physical function declined, those individuals did not necessarily believe that their QOL was declining.

The findings about psychological, existential, and support issues were not too surprising, based on information that many of our patients discuss at each visit. But, I was struck by the possibility that religion and spirituality might play a role in maintaining QOL in individuals with ALS. It was suggested to me by some of the other members of our health-care team that religiousness and spirituality as they relate to QOL were issues we should try to understand better, in order to do the best possible job of helping to maintain and improve QOL in our patients. I must confess that I personally was concerned about bringing up the issue of religion in our ALS clinic, because I have always believed that this is a private issue, and because I did not want individuals to feel awkward or excluded if they had no religious beliefs, or were part of a small religious group with beliefs which differed from the majority. After all, our ALS clinic is, and must remain, a place of comfort and help to all individuals with ALS. This led me to do some reading, and to learn several things of which I was unaware. For example, over 1200 studies have examined the relationship between religious involvement and mental or physical health in other diseases, and the majority have found that religious and spiritual involvement have been associated with better overall health and a higher QOL. Most patients (not just those with ALS) regard their spiritual health as very important, particularly those with terminal illnesses. What about my concern about bringing up a "private" issue like religion in an ALS clinic? It turns out that studies of patients with

other illnesses have shown that most would welcome an inquiry regarding their religious and spiritual needs.

Based on these findings, we have been looking at the role of religion as it relates to QOL in ALS. Those of you who visit the Hershey ALS Clinic are most likely aware that we now have a pastoral care representative, Barb Gascho, as part of our multidisciplinary team. She, our ALS nurse Sue Walsh, and Dr. Barbara Bremer, a psychologist from Penn State Harrisburg, have spearheaded this effort. We recently completed a project in which we studied QOL and religiousness in 49 of our patients with ALS over 5 consecutive visits spanning approximately 1 year. We found that QOL was not related to religiousness at the time of the first visit, but that over time, a significant relationship developed between QOL and religiousness. So, as ALS progresses, religiousness appears to assume an increasingly important role. Does this mean that religion is the answer for all of our patients and their caregivers? Of course not. Any attempts to explore religion and spirituality must respect the fact that there are persons with ALS for whom QOL is not based on these factors, and that those individuals must receive the same level of care as our other patients, and must not feel awkward or out of place in our clinic. As long as this is clearly understood and respected, I believe that spirituality and religion can be one of many items we explore as we seek ways to maintain and improve QOL for our patients and their families.