

Differences in quality of life modalities give rise to needs of individual support in patients with ALS and their next of kin

ANNELI G. OLSSON, R.N., M.SC., INGA MARKHEDE, R.N., SUSANN STRANG, R.N., PH.D.,
AND LENNART I. PERSSON, M.D., PH.D.

Department of Neurology, Institute of Clinical Neuroscience and Institute of Neuroscience and Physiology, Sahlgrenska University Hospital, Göteborg, Sweden

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ABSTRACT

Objective: The aim of this study was to examine health-related quality of life (HRQoL), individual QoL, anxiety and depression in patients with amyotrophic lateral sclerosis (ALS) and their next of kin in relation to patients' physical function over time.

Methods: 35 patients and their next of kin were studied using the Short Form-36 Health Survey (SF-36), Schedule for Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW), and Hospital Anxiety and Depression Scale (HADS) and patients also by the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised and the Norris scale every fourth to sixth month, one to four times.

Results: Changes were found over time in both patients and their next of kin in the SF-36 but not in the SEIQoL-DW or HADS. Patients rated worse than their next of kin in the SF-36 physical subscales and next of kin rated worse than the patients in the global QoL score in SEIQoL-DW. Health, hobbies, and total relations were important areas in the SEIQoL-DW among all participants, but some important areas also differed between the patients and their next of kin. In most important areas among the pairs, the next of kin estimated their functioning/satisfaction worse than patients estimated their functioning/satisfaction.

Significance of results: There were few changes over time in the QoL among the participants. Although most of the estimates in patients and their next of kin were equal, there were also some differences. These results emphasize the importance of support for both patients and their next of kin and that support ought to be given on both individual bases and together in pairs. The SEIQoL-DW might give signposts in the care through the course of the disease about what should be focused on to increase satisfaction of the important areas of life and might help the person to find coping strategies to handle his or her life situation.

KEYWORDS: ALS, Anxiety, Caregiver, Next of kin, Quality of life

INTRODUCTION

Motor neuron diseases (MND), including amyotrophic lateral sclerosis (ALS), are characterized by a progressive degeneration of upper and lower motor neurons. Depending on the location of the degeneration in

ALS, it gives rise to progressive symptoms such as weakness, spasticity and hyperreflexia, speech and swallowing problems, muscular atrophy, wasting, fasciculation, and hyporeflexia (Winhammar et al., 2005). The survival time from the first symptoms is a few years (Worms, 2001; Forbes et al., 2004), but about 10% survive 5 years or more (Forbes et al., 2004). The most common cause of death is respiratory failure (Neudert et al., 2001a; Winhammar et al., 2005) with a peaceful and not a choking death (Neudert et al.,

Address correspondence and reprint requests to: Anneli G. Olsson, Department of Neurology, Sahlgrenska University Hospital, S 413 45 Göteborg, Sweden. E-mail: anneli.g.olsson@vregion.se

2001a). ALS is an incurable disease that can cause both physical damage and psychosocial problems. Palliative care and support with a focus on the families' specific needs and wishes are needed from the time of the diagnosis throughout the course of the disease.

Most measurements of patients' quality of life (QoL), anxiety, and depression are made at one single examination, and results have been found to vary. This may depend on the use of different methods and instruments (Bromberg & Forsheiw, 2002; Chio et al., 2004; Bungener et al., 2005; Wicks et al., 2007). It has been reported that patients' health-related quality of life (HRQoL) deteriorates whereas individual QoL is fairly constant over time (Neudert et al., 2004). The Physical Component Summary (PCS) was found to decrease over time whereas the Mental Component Summary (MCS) in SF-36 did not (Norquist et al., 2003; De Groot et al., 2007). Most patients have no or a low level of anxiety or depression at one single examination (Bungener et al., 2005; Wicks et al., 2007) and over time (Rabkin et al., 2005; Gauthier et al., 2007). It has been suggested that individual QoL, MCS in SF-36, anxiety, and depression do not interrelate with physical function (Norquist et al., 2003; Neudert et al., 2004; De Groot et al., 2007; Krampe et al., 2008; Vignola et al., 2008) whereas PCS in SF-36 does (Norquist et al., 2003; De Groot et al., 2007).

QoL has been claimed to be moderately high and the level of depression low in both patients and caregivers (Trail et al., 2003), but it also has been shown that patients have better individual QoL (Bromberg & Forsheiw, 2002). Patients' QoL and depression have been found to be relatively constant whereas their caregivers have shown an increase in depression and burden (Gauthier et al., 2007). In contrast to those results, it has been reported that spouse carers do not have increased anxiety and depression but do show an increase in psychological distress over time (Goldstein et al., 2006).

A diagnosis of ALS emotionally affects both the patient and the next of kin. To increase our understanding of the physical and emotional consequences that the disease might have, both the patient and the next of kin must be studied in terms of health-related and individual QoL and the possible presence of anxiety and depression. It may be possible to gain a broader perspective of the QoL in patients with ALS and their next of kin if matched pairs and not only groups of patients/next of kin are studied over time with different QoL instruments. The aim of this study was to examine HRQoL, individual QoL, and self-estimates of anxiety and depression in patients with ALS and their next of kin in relation to patients' physical function over time.

METHODS

Participants and Demographics

Patients with probable or definite ALS according to the El Escorial criteria (Brooks, 1994) who were under treatment by the ALS/MND team at Sahlgrenska University Hospital from January 2006 onward were asked to participate in the study. Patients or next of kin who were in such physical or psychological condition that they were not able to give informed consent and patients who were in a terminal stage of the disease were excluded.

Forty-seven consecutive patients were eligible for inclusion in the study. One man was excluded because of poor performance in the Swedish language and four men and one woman did not wish to participate. Because of the focus on patients versus next of kin, only patients with a next of kin were included, which excluded a further six patients. One of these six patients was also excluded because of a cognitive impairment. The final number was 35 patients and 35 next of kin at the start of the study. At entry to the study, the mean age of the patients was 63.4 years (median 64 years, range 28–84 years) and of their next of kin 61.3 years (median 64.5 years, range 27–86 years).

All patients lived at home during the study. Next of kin was defined as a person closely related with a near contact to the patient. This term was found to be suitable, because not all of them assisted the patients in their daily life. Thirty of the next of kin were married or cohabited with the patient, three were children, one was a sister, and one had previously been married to the patient.

Instruments

Patients and their next of kin estimated their HRQoL by the Short Form-36 Health Survey (SF-36; Sullivan et al., 1995), their individual QoL by the Schedule for Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW; Hickey et al., 1996), and their experience of anxiety and depression by the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The patients' physical function was estimated by two physical functional scales, the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R; Cedarbaum et al., 1999) and the Norris scale (Norris et al., 1974). At entry to the study, the patients were evaluated by the Mini-Mental State Examination (MMSE; Myers, 1987) to exclude major signs of cognitive impairment.

The SF-36 includes 35 items divided into eight multi-item scales, physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role

emotional (RE), and mental health (MH), and one single item reporting health transition over the past year (Sullivan et al., 1995; Sullivan & Karlsson, 1998). These eight scales are divided into two major dimensions of health: the Physical Component Summary (PCS) and the Mental Component Summary (MCS; Persson et al., 1998). Higher scores reflect better QoL (Sullivan et al., 1995).

The SEIQoL-DW is a semistructured interview in which the person nominates the five most important areas of life. Functioning/satisfaction in each area are then rated on a visual analogue scale where 0 is "as bad as can be" and 100 is "as good as can be." The importance of the five areas is then weighted against each other. The person's self-rating of functioning/satisfaction in each area is subsequently multiplied by the corresponding area weight. This gives five products that are summarized to obtain a global quality of life score that ranges from 0 to 100. Higher scores reflect better QoL (Hickey et al., 1996; Neudert et al., 2001b).

The HADS estimates anxiety (HADA) and depression (HADd) in two subscales with seven items each. The subscales are rated on 4-point scales (0–3). A score of 7 or less indicates no case of anxiety or depression, 8–10 points indicate doubtful cases and scores over 11 indicate definite cases. Higher scores reflect poorer ratings (Zigmond & Snaith, 1983).

The physical function of patients was rated by the ALSFRS-R (Cedarbaum et al., 1999) and the Norris scale (Norris et al., 1974). ALSFRS-R measures gross and fine motor tasks and bulbar and respiratory functions. The scores range from 0 to 40, where 40 is normal functioning (Cedarbaum et al., 1999). The Norris scale is a 100-point scale where higher levels indicate better function. It measures bulbar, respiratory, trunk, arm, leg, and general domains, reflexes, fasciculation, and muscle atrophy (Norris et al., 1974; Winhammar et al., 2005). Both scales were used because they partly rate some different items of physical function. In the same study group, Olsson et al. (in press) reported decreased physical function over time in the ratings by ALSFRS-R and the Norris scale (Table 1).

Procedure

Patients and their next of kin were consecutively included in the study from January 2006. The study ended in December 2007. Patients were examined every fourth to sixth month, with an ambition of six months, one to four times, by the ALS/MND team at the Department of Neurology, Sahlgrenska University Hospital. The SF-36 and HADS forms were sent home to the participants, who were requested

to complete the questionnaires on their own before the following visit to the physician. The physician examined the patients using the ALSFRS-R and Norris scales. The patients and next of kin were then seated in separate rooms and interviewed by the research nurses with the SEIQoL-DW. At entry to the study, one research nurse tested all patients with the MMSE.

Analysis

Data were paired and two-tailed tested. A level of $p < .05$ was considered significant.

To avoid an erroneous interpretation of multiple testing of changes over time in the instruments, a regression coefficient was calculated for each patient and next of kin. The coefficient describes the slope of the graph, where x -values are the time of the visits (at 0, 6, 12, and 18 months) and y -values are the variables investigated. A regression calculation was made for every patient/next of kin with more than one visit, and every regression coefficient was given an equal weight regardless of whether the participant attended the study sessions two, three, or four times. The participants who were used to calculate the regression coefficients were taken from those who still remained in the study at Visit 2 and onward. Using the slopes/coefficients, Fisher's test for paired comparison was employed to test whether the coefficient was different from 0, that is, whether there was a change over time.

Paired comparisons between patients and their next of kin were analyzed with the Wilcoxon Signed Ranks Test. The Mann–Whitney test was used to analyze differences between genders. Correlations between the physical functional scales and SF-36, SEIQoL-DW, and HADS were analyzed by Spearman's rho.

Ethics Approval

Ethical approval was obtained from the Regional Ethical Review Board in Gothenburg, approval No. 297-05.

RESULTS

Changes over Time in SF-36, SEIQoL-DW, and HADS

Among patients, changes were found over time in the subscales PCS, PF, and GH in SF-36. Next of kin had changes over time in the subscales MCS, PF, BP, and RE. The global QoL score in SEIQoL-DW and the HADS showed no changes over time in either the patients or their next of kin (Table 1). There were no differences with respect to gender.

Table 1. Changes over time in patients and their next of kin.

	Baseline	Second visit	Third visit	Fourth visit	Mean, SD, n for regr. coefficients	Changes over time
Patients						
SF-36 PCS total	33.0 (11.8)/35	31.1 (9.6)/32	29.5 (11.4)/26	30.0 (11.7)/9	-0.37 (0.89)/32	*
SF-36 MCS total	45.9 (13.8)/35	45.5 (12.4)/32	45.7 (13.0)/26	46.1 (16.0)/9	-0.08 (1.04)/32	
SF-36 PF total	42.0 (35.9)/35	32.8 (30.4)/32	28.3 (31.9)/26	30.6 (28.8)/9	-1.49 (2.59)/32	**
SF-36 RP total	31.4 (42.2)/35	35.9 (40.6)/32	27.9 (38.9)/26	27.8 (34.1)/9	0.35 (5.35)/32	
SF-36 BP total	75.4 (25.7)/35	75.7 (26.0)/32	74.6 (27.5)/26	66.8 (35.2)/9	-0.42 (2.25)/32	
SF-36 GH total	45.7 (21.1)/35	38.6 (18.2)/32	40.0 (20.2)/26	46.1 (26.9)/9	-0.96 (1.59)/32	***
SF-36 VT total	49.0 (27.2)/35	45.3 (22.6)/32	49.0 (21.4)/26	55.0 (21.1)/9	-0.31 (2.06)/32	
SF-36 SF total	67.5 (29.6)/35	69.5 (24.0)/32	64.9 (27.6)/26	66.7 (30.0)/9	-0.28 (3.04)/32	
SF-36 RE total	57.1 (42.5)/35	50.0 (44.0)/32	48.7 (45.4)/26	48.2 (47.5)/9	-0.83 (4.68)/32	
SF-36 MH total	70.7 (22.6)/35	70.0 (16.7)/32	69.1 (19.4)/26	67.6 (20.8)/9	-0.29 (1.42)/32	
SEIQoL-DW global QoL score	79.3 (16.5)/34	75.7 (15.0)/32	76.6 (14.7)/26	66.5 (20.7)/9	-0.28 (1.58)/32	
HADa total	5.94 (4.64)/35	6.28 (4.55)/32	5.81 (4.23)/26	7.00 (4.74)/9	0.03 (0.28)/32	
HADd total	5.43 (4.71)/35	5.25 (3.79)/32	5.19 (4.67)/26	6.00 (4.03)/9	0.03 (0.30)/32	
ALSFRS-R	36.6 (7.6)/35	33.4 (8.5)/32	31.7 (9.4)/26	35.4 (9.1)/9	-0.59 (0.63)/32	***
Norris scale	72.7 (17.8)/35	67.5 (16.7)/32	63.4 (18.9)/26	71.6 (18.4)/9	-1.07 (1.37)/32	***
Next of kin						
SF-36 PCS total	48.6 (10.6)/34	48.9 (9.1)/31	49.6 (9.4)/26	48.8 (11.0)/9	-0.03 (0.61)/32	*
SF-36 MCS total	41.4 (14.2)/34	41.6 (14.8)/31	41.0 (13.5)/26	46.0 (14.7)/9	-0.35 (0.88)/32	*
SF-36 PF total	84.7 (20.8)/35	85.5 (15.6)/31	86.9 (14.6)/26	81.1 (21.5)/9	-0.25 (0.66)/32	
SF-36 RP total	65.0 (41.2)/35	67.7 (36.6)/31	69.2 (37.6)/26	83.3 (35.4)/9	-0.53 (2.60)/32	
SF-36 BP total	77.5 (20.5)/35	70.7 (25.0)/31	73.2 (26.3)/26	75.4 (26.5)/9	-0.68 (1.83)/32	*
SF-36 GH total	66.1 (25.0)/35	69.6 (20.2)/31	66.5 (23.4)/26	67.8 (25.0)/9	-0.12 (1.95)/32	
SF-36 VT total	57.1 (24.5)/35	54.0 (30.1)/31	58.9 (24.8)/26	65.0 (22.2)/9	-0.38 (1.33)/32	
SF-36 SF total	77.1 (24.4)/35	79.0 (25.1)/31	76.0 (22.9)/26	81.9 (23.5)/9	-0.22 (2.08)/32	
SF-36 RE total	62.8 (42.5)/34	62.4 (42.8)/31	57.7 (44.8)/26	74.1 (40.1)/9	-1.52 (2.65)/32	**
SF-36 MH total	68.7 (22.1)/35	69.4 (20.8)/31	70.6 (20.9)/26	74.2 (19.5)/9	-0.40 (1.61)/32	
SEIQoL-DW global QoL score	64.1 (16.4)/34	64.7 (15.7)/30	63.9 (13.6)/26	68.6 (15.1)/9	-0.31 (1.64)/32	
HADa total	7.09 (5.56)/35	7.16 (5.43)/31	6.96 (4.83)/26	5.44 (4.39)/9	0.03 (0.24)/32	
HADd total	4.69 (4.30)/35	5.10 (4.24)/31	5.38 (3.94)/26	3.00 (2.60)/9	0.07 (0.28)/32	

Mean (\pm standard deviation)/number of patients/next of kin at every visit and for the regression coefficients. *P* levels in the table indicate deterioration over time from baseline to the last visit for each patient/next of kin.

*significant time effect $p < .05$, **significant time effect $p < .01$, ***significant time effect $p < .001$.

Comparisons between Patients and Their Next of Kin

At Visit 1, patients estimated poorer PCS, physical functioning, role physical, and general health ($p < .003$) in SF-36 than did the next of kin. The next of kin had a poorer global QoL score in SEIQoL-DW than the patients ($p < .001$). There were no differences in the changes over time in paired comparisons between patients and their next of kin in the SF-36, SEIQoL-DW, or HADS except in SF-36 physical functioning ($p < .05$), where patients' physical functioning decreased. The differences found between the

pairs at Visit 1 were similar at following revisits in the study. The patients still had poorer estimates in the SF-36 PCS and in the subscales of PF, RP, and GH, and their next of kin still had poorer estimates in the global score in SEIQoL-DW, which can be seen in the mean values (Table 1).

Areas in SEIQoL-DW

Patients and their next of kin indicated 96 areas as being important in the SEIQoL-DW. After a reduction of those areas, patients showed 36 areas and their next of kin 31 areas. To prevent the areas

from concealing the meaning of the content and preventing risks that the areas might show an overlap in item content, we chose not to further reduce the areas. The areas chosen did not change a great deal over time in either the patients or their next of kin.

Both patients and their next of kin estimated relations such as children/grandchildren, family, marriage, and friends as important areas of life. However, the functioning/satisfaction was often better among patients than their next of kin. There were also some differences between the pairs in the chosen areas. Patients estimated, for example, hobbies as being more important whereas next of kin estimated employment/education and travel. The most important areas at each visit and their ratings of functioning/satisfaction are shown in Table 2. Figures 1 and 2 show the most important areas at Visit 1. *Hobby* was defined as less active interest areas (such as betting on horses, having household pets, and watching movies) and *leisure* was defined as more active areas of interest (such as outdoor activities).

Correlations between Physical Functional Scales ALSFRS-R and Norris Scale versus SF-36, SEIQoL-DW, and HADS

Among the patients, ALSFRS-R correlated with PF ($p = .025$, $r = .396$) and MH ($p < .001$, $r = .566$) in SF-36 over time. The Norris scale correlated with patients PCS ($p = .002$, $r = .518$), PF ($p < .001$, $r = .471$), BP ($p = .016$, $r = .423$) and MH ($p = .04$, $r = .365$) in SF-36 over time. No other correlations were found between the physical functional scales and SF-36, SEIQoL-DW, or HADS over time in patients or their next of kin except between patients' ALSFRS-R and next of kin physical functioning ($p = .024$, $r = .397$).

DISCUSSION

Our study showed an absence of change over time in SEIQoL-DW and HADS. Among patients, PCS, but not MCS in SF-36, decreased over time, which is in agreement with other studies (Norquist et al., 2003; De Groot et al., 2007). The lower rating in PCS is explained by the progression of the disease. The decreases in the next of kin in SF-36 might be explained by patients' increased physical needs of help and the pain of privy in their predictive loss of their spouse or relative. Burden among the next of kin over time will probably increase, which is in accordance with other studies (Chio et al., 2005; Gauthier et al., 2007). Anxiety was found to be in a borderline range and depression in a normal range in spouse carers (Goldstein et al., 2006), which is in agreement with our study: No changes were found over time in the

HADS, but the mean values for anxiety were on a level between normal and slightly increased at the two first study visits. It might therefore be important that attention is paid to these factors when caring for these families.

Few differences were seen over time between patients and their next of kin. However, it was found in the physical subscales in SF-36, where patients had poorer ratings, and in the individual QoL, where next of kin had poorer ratings. It needs to be observed that, even if there were few differences between the pairs over time, the differences between the patients and their next of kin in each pair at Visit 1 remained over time. Patients had still worse estimates in some of the subscales in SF-36 and their next of kin had worse estimates in the global score in SEIQoL-DW over the study visits. It seems that different parts of the spectrum of QoL are affected in patients and their next of kin. For this reason, it is important to give individual support according to need during the entire progression of the disease.

Patients' global scores in SEIQoL-DW in our study confirm the findings of both single investigations and studies conducted over time (Chio et al., 2004; Neudert et al., 2004; Felgoise et al., 2009). In our study and one other study (Bromberg & Forsheiw, 2002), next of kin/caregivers showed poorer global scores than their patients. A possible explanation is a greater burden among the next of kin that might cause them to renounce their own needs.

The areas chosen were often found in different varieties of relations, which might explain why they were nearly unchanged over time. If areas with a greater number of physical activities had been chosen, there could probably have been a greater change because of the successive deterioration of physical function. Both patients and next of kin reported health and relations such as children/grandchildren, friends, marriage, and family (in total) to be important areas of life. Patients more often described hobbies whereas next of kin more often described employment/education as important areas. The differences might depend on patients' loss of physical function. The patients were not able to work whereas their next of kin were healthy and worked outside the home, which was given great priority. In almost all equally important areas of life found in both patients and their next of kin, the next of kin estimated worse functioning/satisfaction than the patients (Table 2). That shows the difficulty in the next of kin's life situation, and these findings further emphasize the importance of supporting them. This is in accordance with findings by Nolan et al. (2008), who found that caregivers expressed the need of psychological, physical, and spiritual support (Nolan et al., 2008).

Table 2. Most important areas are shown in percentage of the number of participants that chose the area and mean values are calculated in functioning/satisfaction

	Visit 1		Visit 2		Visit 3		Visit 4	
	%	Functioning/satisfaction	%	Functioning/satisfaction	%	Functioning/satisfaction	%	Functioning/satisfaction
Patients								
Children/grandchildren	65	85	53	90	58	91	78	75
Friends	53	82	56	72	65	77	56	72
Marriage	41	87	28	75	23	69		
Health	32	45	31	63	35	47	56	67
Family (in total)	26	90	47	79	31	80		
Hobby	26	56	28	72	31	73		
Health among relatives	21	87	19	90	23	82		
Relatives					27	67		
Meal time							33	86
Get out							33	44
Independence							33	42
Leisure			19	57				
Next of kin								
Health	54	75	50	60	42	64	67	67
Friends	49	64	57	70	54	67	56	64
Children/grandchildren	44	76	50	79	35	78	44	78
Family (in total)	34	69			35	55	33	77
Employment/education	35	63	37	67	38	74	44	57
Travel	26	39			27	57		
Marriage	26	54					33	65
Housing			27	68	27	70		
Own time/freedom			30	42				
Hobby			27	49				
Leisure							44	60

At later study visits, patients also estimated independence, getting out, and meal times as important areas in the SEIQoL-DW. Even if there were few changes over time in the chosen areas, these areas might supervene because of the decrease in physical

function. Travelling and own time/freedom were mentioned more often as important areas by the next of kin. It is possible that their own life and needs diminish in importance because their priority is to help the sick person. Housing was also an important area among the next of kin. Fear of losing the house/

Most important areas in SEIQoL-DW in the group of patients

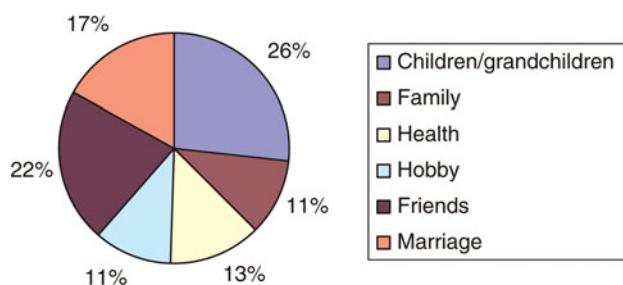


Fig. 1. (Color online) Most important areas in SEIQoL-DW among patients at Visit 1. Relations constitute 76% of important areas.

Most important areas in SEIQoL-DW in the group of next of kin

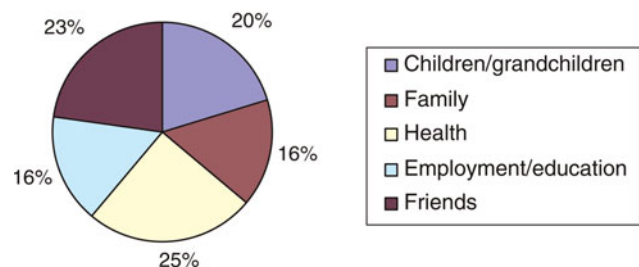


Fig. 2. (Color online) Most important areas in SEIQoL-DW among next of kin at Visit 1. Relations constitute 59% of important areas.

apartment because their economic situation had become worse or the fear that the patient would become too ill to live at home, forcing them to seek housing that better conformed to the patient's needs might underlie the ratings of these factors. Other studies have also found important areas to be family, friends, health, and hobbies. Spirituality and religion were found to be other important areas (Lo Coco et al., 2005; Felgoise et al., 2009). These two areas were infrequently described in our study. The differences in our results and those of other researchers might have to do with cultural differences, because Sweden is a strongly secularized country.

Every patient and next of kin who had participated more than one time was given one regression coefficient, and every regression coefficient had the same rating regardless of whether the person participated two, three, or four times. The significant changes over time in Table 1 indicate decreased values regardless of whether they left the study after two, three, or four visits. This makes the fourth visit less crucial: For many patients, the participation in the study ends at Visit 2 or 3. Participants left the study successively owing to an inability to participate because of the progression of the disease or death or because of an inability to attend further visits before the study ended. Patients who participated all four times were usually in better physical condition than a patient who participated only one or two times. For that reason, the mean values at the third or fourth visit were sometimes equal to or even better than the mean values at the start of the study. To reduce risks of problems with mass significance, we focused on patterns and not single p values. However, as there were fluctuations of the QoL in patients and next of kin between the different visits, the method of using regression coefficients as a basis for evaluating QoL during the course of the disease smoothes the individual values at each visit, which hides some of the significances found when statistics are analyzed at each study interval point.

Patients diagnosed with ALS and their next of kin all go through a difficult period when they receive the diagnosis. To gain greater knowledge of their life situation and whether and how it differs over time, longitudinal studies are needed that focus on both individual and health-related QoL as well as anxiety and depression. In our study it seems that patients are more affected in HRQoL whereas next of kin are affected in both HRQoL and individual QoL. Both patients and next of kin show some changes over time in important areas of life. Our results indicate the importance of support throughout the course of the disease to both patients and their next of kin. Because ALS is an incurable disease that, sooner or later, proceeds into a palliative state, the aim must

be to give as good care as possible according to the patients' and their next of kin's own needs. Because there are some different needs between the pairs, support should preferably be given both individually and in the patient/next of kin pair. With support, supervision, and confirmation of the difficult situation, there might be a possibility to improve QoL.

Information gathered by using the SEIQoL-DW might also give physicians, nurses, and other staff indications about what they should focus on to help the family achieve increased functioning/satisfaction in the areas of life that are felt to be important. It might also be easier for patients and their next of kin to find coping strategies to handle the situation when areas have been clarified. A possibility for patients and their next of kin to be able to talk with each other more openly might allow a deeper understanding of the other's priorities and needs and bring family members closer to each other.

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