

Assessing subjective quality of life domains after multiple sclerosis diagnosis disclosure

Katia Mattarozzi PhD,* Federica Casini PhD,† Elisa Baldin MD,‡ Martina Baldini NP,¶
 Alessandra Lugaresi MD,§ Paola Milani LCP,** Erika Pietrolongo PhD,†† Alberto
 Gajofatto PhD,‡‡ Maurizio Leone MD,¶¶ Trond Riise PhD,§§ Luca Vignatelli MD,***†††
 Roberto D'Alessandro MD‡‡‡ and on behalf of G.E.Ro.N.I.Mu.S. group

*Professor, †Fellow, ¶Post Graduate Student, Department of Experimental, Diagnostic and Specialty Medicine, University of Bologna, Bologna, ‡Fellow, †††Professor, IRCCS Institute of Neurological Sciences of Bologna, Bologna, §Professor, ††Fellow, Department of Neuroscience Imaging and Clinical Sciences, Multiple Sclerosis Center, University "G. D'Annunzio", Chieti-Pescara, **Fellow, Department of Neuroscience, S. Anna Hospital, University of Ferrara, ††Medical Doctor, Department of Neurological and Movement Sciences, University of Verona, Verona, ¶¶Medical Doctor, Neurology Unit, Department of Medicine, IRCCS Casa Sollievo della Sofferenza, San Giovanni Rotondo, Italy, §§Professor, Department of Global Public Health and Primary Care, Bergen University, Bergen, Norway, ***Medical Doctor, Local Health Trust, Bologna and †††Medical Doctor, Agenzia sanitaria e sociale regionale – Regione Emilia-Romagna, Bologna, Italy

Abstract

Background and Objective An investigation of the domains Italian patients with multiple sclerosis (MS) named as constituting their quality of life over time.

Design We assessed, in 68 patients, QoL domains using the Schedule for the Evaluation of Individual QoL: (a) before MS diagnosis disclosure, (b) thirty days after disclosure, and (c) after one and (d) four years' follow-up.

Results The life domains most frequently named by patients were as follows: Family, Work and Finance, Hobbies, Health, Relationship with Friends and Job Effectiveness. Only Health and Job Effectiveness domains varied with time. The Health domain became a critical dimension when MS diagnosis was revealed. In addition, patients tended to be more satisfied with their health after disclosure compared to pre-diagnosis. Job Effectiveness seemed to be an important aspect until 1 year after diagnosis disclosure, but it tended to become less crucial over time. Family seems to be the most important domain over time, and psychological adaptation to MS seems to be characterized by a reconceptualization of aspects that revolve around oneself, such as professional success, rather than relational or affective factors.

Conclusions Evaluating the most relevant life domains for patients and their alteration over time may provide practitioners with an important tool in making health-related decisions, thus improving health outcomes and QoL.

Correspondence

Katia Mattarozzi, PhD
 Department of Experimental,
 Diagnostic and Specialty Medicine
 University of Bologna
 V.le Bertoni Pichat, 5
 40127 Bologna
 Italy
 E-mail: katia.mattarozzi@unibo.it

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Introduction

Monitoring individual patients' quality of life (QoL) is a valuable asset for care planning, and provides important information as to the impact of illness and care effectiveness.

Several studies^{1–8} have investigated QoL in people with multiple sclerosis (MS). In particular, in a recent study⁹ we suggested that an early disclosure of MS diagnosis improves QoL. Awareness of MS diagnosis, with the provision of disease information, seems to reduce the stressful condition of uncertainty and enhance the process of adapting to the disease. As studies conducted in several clinical populations suggest, after diagnosis disclosure, patients adjust their goals and expectations^{10–14}. This psychological adjustment could be responsible for patients' QoL improvement despite the awareness of a chronic illness and likely disabilities. In literature, QoL assessment is mainly based on a nomothetic approach¹⁵, which assumes physical limitation as the most important factor in determining patients' QoL. Standardized instruments have emerged from this approach, and include a pre-defined set of domains, often focusing on health status [e.g. Multiple Sclerosis QoL-54 (MSQoL-54)]. The use of health-related questionnaires provides valuable information, but does not reflect patients' values, or, rather, it indicates them only in part and only implicitly, through the impact of disability on patients' standards. Furthermore, the health-related questionnaires do not investigate the capacity of the individual to achieve his/her life plans, or the process of patient adaptation to the disease as a whole. As pointed out in a recent study¹⁶, the generic preference-based measures of health-related QoL were not exhaustive in capturing the domains that are important for people with MS and that are impacted upon by the clinical condition. It is important to consider that, as the study by Rothwell and co-workers underlined (1997)¹⁷, patients with MS, and those with other chronic diseases, seem to be less concerned than their clinicians about physical disability in their illness.

To our knowledge, no studies to date have evaluated how patients who receive a diagnosis of MS change their internal standards, values and conceptualization of QoL over time. In this study, we used longitudinal data obtained from the Schedule for the Evaluation of Individual QoL (SEIQoL),¹⁸ with the aim of identifying which aspects of life patients with MS consider to be essential for their well-being and whether these aspects change over time. Using a qualitative approach, we examined the QoL domains that patients named in multiple interviews (i.e. from the start of diagnostic work-up, namely when patients were unaware of their diagnosis, and at three further intervals: immediately after diagnosis disclosure, and at 1 and 4 years after). In particular, we extracted the SEIQoL qualitative data derived from a more extensive project on the Prognosis of MS (Gruppo Emiliano-Romagnolo Neurologici In Multiple Sclerosis – G.E.Ro.N.I.Mu.S.^{9,19}).

Materials and methods

In this study, we used data from a more extensive study on the prognosis of MS (G.E.Ro.N.I.Mu.S). Specifically, we extracted qualitative data derived from the SEIQoL, one of the QoL instruments administered to the recruited patients in the G.E.Ro.N.I.Mu.S study^{9,19}.

Participants

Eligible participants were patients who had shown symptoms suggestive of MS in the last 6 months or less. Exclusion criteria were as follows: (i) age under 18 years; (ii) cognitive impairment as judged by the treating neurologist; and (iii) inability to undergo MRI to assess MS diagnosis according to McDonald's 2005 criteria²⁰. Patients were recruited in 16 Neurological Units that were part of the G.E.Ro.N.I.Mu.S. study. The study was approved by the Ethical Committee on Human Research at each affiliation of the Units involved, and informed consent was obtained from all participants.

Assessment

QoL was assessed by SEIQoL – visual analogue scale (SEIQoL-VAS)¹⁸. SEIQoL-VAS is a semi-structured interview in which patients are invited to freely nominate the five domains they currently consider to be the most important in their lives, followed by a rating, on a vertical visual analogue scale (VAS, score range: 0–10), of current satisfaction and importance of each of the chosen areas. For more details concerning the method of administration of SEIQoL, see the related manual^{18,21}.

Neurological disability was assessed using the Expanded Disability Status Scale (EDSS)²².

Study procedure

The enrolment of patients has been described in detail in previous published papers^{19,22}.

Researchers (a psychologist, in most cases) from each centre were instructed on how to administer SEIQoL. An expert conducted the training during a one-day session.

To encourage a frank and open discussion, the clinician–researcher was not directly involved in patient care. Specifically, researchers introduced the interview by explaining: ‘I would like you to help me to understand how you feel in this period. Satisfaction and happiness in life depend on fundamental values and activities that could be different for each of us. In fact, what is important for me or for a friend of yours might not be as important for you. Moreover, we often realize what is important, and how much, when something changes or when we think it might change. Please list the five dimensions/aspects that you consider to be the most important in your daily life and that determine your QoL’. Researchers recorded a meaningful summary of what the patients said. At the end of this phase, the clinician–researcher categorized the answers, with the patient’s agreement, into discrete categories on the basis of the most common life domains in literature, for example family and hobbies^{13,21,23,24}. As far as the Work dimension is concerned, the researcher had to distinguish between two categories based on the specific content of the

patient’s response: one category refers to the economic aspect (i.e. Work and Finance) and the other regards personal fulfilment (i.e. Job Effectiveness). Once the five general categories have been identified, patients rated, on a VAS, how satisfied they felt regarding each area and the importance that it had for them. The interview lasted approximately 30 min.

Patients were assessed in a private setting at study inclusion (T0), 30 days after diagnosis disclosure (T30) and one (T1y) and 4 (T4y) years after diagnosis. Diagnosis of MS was made according to the 2005 version of McDonald’s criteria²⁰, and it was considered to be disclosed after the neurologist had informed patients of the nature of the condition and therapeutic procedures, including possible alternatives and possible outcomes.

Data analysis

Categorization of QoL domains

Life domains elicited from participants during the completion of the SEIQoL-VAS were extracted. Three researchers independently reviewed the life domains derived from the interview, and classified any domains that did not fit into the most common categories^{13,21,23,24}. In almost all cases, the patients’ answers had been correctly placed into categories by the clinician–researchers. In the few instances in which the answers needed to be recategorized (inter-rater agreement, as assessed by kappa coefficient, was 0.94), the researchers decided on the correct category through discussion.

Statistical analysis

We recorded the frequency (%) of each domain across all assessments.

Cochran’s Q and McNemar statistics were used to compare the frequency of the named domains between the four assessments (only domains reported by nearly 50% of the patients were included in analyses). α -values were corrected according to Bonferroni adjustment; in multiple comparisons, values <0.012 were considered as statistically significant.

We performed Fisher's exact test to explore the association between education (patients were categorized in accordance with their level of schooling within the Italian school system as: fewer than 8 years of education; from 8 to 13 years of education; more than 13 years of education) and the frequency of named dimensions.

To explore the changes in the rating of importance and satisfaction, independently repeated-measure ANOVAS (T0 vs. T30 and T30 vs. T1y vs. T4y) were conducted for each of the six most represented domains (i.e. domains reported by nearly 50% of the patients).

In order to ascertain whether the results of our study could be due to a selection bias, we performed two additional *post hoc* analyses: (i) by means of Fisher's exact test, we compared the T0 scores for each life dimension of drop-out patients (i.e. patients that did not have four observations, $n = 36$) and those that completed the study ($n = 32$); (ii) using McNemar test, we compared T30 with baseline (T0) scores for all patients who had data at these two time points ($n = 55$).

Results

Sample

Sixty-eight patients completed the initial screening [49 female, mean age 33.4 ± 6.9 ; mean years of education 12.2 ± 3.2 ; job: 18 employees in the private sector, 16 industrial workers, 10 entrepreneurs, 6 artisans, 5 civil servants (e.g. administrative workers at the city hall or in a public hospital)], 4 freelancers, 3 teachers, 3 nurses, 2 businessmen, 1 professional athlete). Fifty-eight patients came from the north of Italy, while the remaining 10 came from a central region of Italy. Of the 68 patients who completed the initial screening, 50 patients knew that they had a clinically isolated syndrome (CIS) disclosed by a previous centre, while 18 patients did not know their diagnosis. At the end of the screening, 61 received a disclosure of MS and data at T30 were fully available for 55 patients (7 patients did not fulfil the diagnostic criteria and remained classified as CIS, 4

patients withdrew the informed consent after MS diagnosis disclosure, and for 2 patients, data at T30 were incomplete). All 55 patients had clinically definite relapsing–remitting MS. Clinical characteristics of the patients are reported in Table 1. In the subsequent follow-up, some patients dropped out mainly due to incomplete interviews, patient migration to other neurological units or missed follow-up visits (see Table 1 for the N sample). Of the 32 patients who completed the study, 8 patients changed their job between T30 and T1y, while 3 patients changed their job between T1y and T4y.

QoL data

Table 2 lists the life domains named by participants and, for each domain, shows the proportion of patients at different times of assessment. Family, Work Finance, Hobbies, Health, Relationship with Friends and Job Effectiveness were the life areas that were most frequently named by participants (nearly 50% of patients). In Appendix A, we report a list of specific aspects elicited from patients that actually constitute the extracted life domain together with some examples of what participants specifically said.

For brevity, comparisons that failed to reach statistical significance are not reported. Two life domains varied as a function of time: Health ($Q = 24.12$; $P < 0.001$) and Job Effectiveness ($Q = 17.01$; $P < 0.001$). Specifically, the McNemar test revealed that Health was significantly less frequently named by patients at the start of the screening period compared both to 30 days after diagnosis disclosure and to the subsequent follow-ups (T0 vs. T30, T1y and T4y $p_s < 0.001$); there were no differences between T30 and T1y, T2y. Moreover, Job Effectiveness was significantly less frequently named at T4y compared to T1y, T30 and T0. To explore changes in the rating of importance and satisfaction, independently repeated-measure ANOVAS (T0 vs. T30 and T30 vs. T1y vs. T4y), were conducted for each of the six most represented domains (i.e. Family, Work Finance, Hobbies, Health, Relationship with Friends and Job Effectiveness). The only significant, or near-significant, comparisons were the

Table 1 Clinical, MRI characteristics and therapies

	Diagnosis screening start point (T0) <i>n</i> = 68	30 days after diagnosis disclosure (T30) <i>n</i> = 55	1 year follow-up (T1y) <i>n</i> = 50	4 years of follow-up (T4y) <i>n</i> = 32
<i>EDSS</i>				
<i>Nr. pts</i>				
0.0–2.5	61	54	47	28
3.0–6.0	7	1	3	4
>6.0	0		0	0
<i>MRI Lesions</i>				
<i>Median (IQR)</i>				
T2 lesions	10.5 (4–21.5)	–	–	–
Gd-enhancing lesions	0 (0–1.5)			
<i>CSF</i>				
<i>Nr. pts</i>				
	45	–	–	–
<i>Treatment</i>				
<i>Nr. pts</i>				
IV Steroid	54	–	14	10
Immunomodulatory	2		24	23
Other	2		2	2

Table 2 QoL Domains named by participants listed on the basis of the frequency (%)

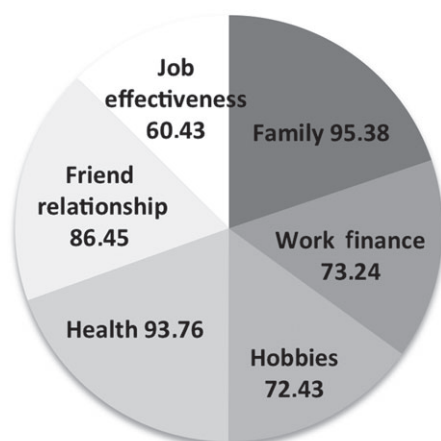
Diagnosis screening start point (T0) <i>n</i> = 68	30 days after diagnosis disclosure (T30) <i>n</i> = 55	1 year follow-up (T1y) <i>n</i> = 50	4 years follow-up (T4y) <i>n</i> = 32
Family (94.1)	Family (98.1)	Family (97.9)	Family (97.0)
Work finance (64.7)	Health (75.9)	Health (79.2)	Health (82.5)
Hobbies (57.4)	Work finance (72.2)	Work finance (68.8)	Work finance (75.8)
Health (55.9)	Hobbies (66.7)	Hobbies (62.5)	Relationship with friend (69.7)
Relationship with friend (55.9)	Relationship with friend (63.0)	Relationship with friend (58.3)	Hobbies (66.7)
Job effectiveness (48.5)	Job effectiveness (50.0)	Mental health (45.8)	Mental health (33.3)
Mental health (44.1)	Mental health (42.6)	Job effectiveness (33.3)	Social life/activities (27.3)
Social life/activities (25.0)	Social life/activities (27.8)	Social life/activities (33.3)	Partner (27.3)
Partner (25.0)	Partner (22.2)	Partner (27.1)	Job effectiveness (24.8)
Religion (13.2)	Religion (11.1)	Religion (12.5)	Religion (12.1)
Sex (5.9)	Independence (7.4)	Sex (4.2)	Sex (3.0)
Life environment (4.4)	Life environment (5.6)	Life environment (4.2)	Clinical staff relationship (3.0)
Independence (2.9)	Sex (3.7)	Independence (2.1)	Independence (–)
Clinical staff relationship (–)	Clinical staff relationship (3.7)	Child care (2.1)	Child care (–)
Child care (–)	Child care (1.9)	Clinical staff relationship (–)	Life environment (–)

following (see Fig. 1): Job Effectiveness was rated less important at T4y compared to both T30 and T1y (87.31 ± 17.24 vs. 87.38 ± 18.04 vs. 39.15 ± 45.75 ; $F(1,24) = 10.15$, $P = 0.003$, $\eta_p^2 = 0.46$; T30 vs. T4y $P = 0.012$, T1y vs. T4y $P = 0.020$). Health satisfaction tended to be higher immediately after diagnosis disclosure

(46.32 ± 28.46 vs. 56.84 ± 24.27 , $F(1,24) = 3.49$, $P = 0.074$, $\eta_p^2 = 0.13$). The importance and satisfaction did not differ as a function of time in other life dimensions.

A repeated-measure ANOVA suggested that disability (i.e. EDSS score) did not vary significantly as a function of time. Moreover, we

(a) Rating of Importance (value at T30)



(b) Rating of Satisfaction (value at T30)

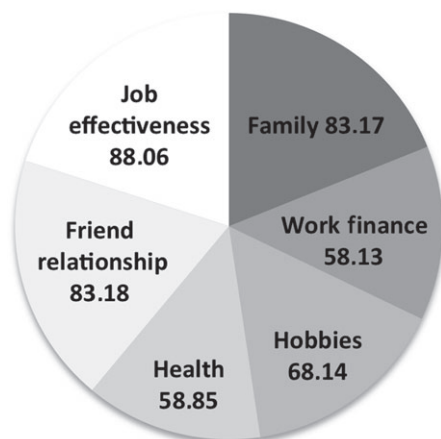


Figure 1 Rating of Importance and Satisfaction attributed to the most recurrent life domains named by participants 30 days after diagnosis disclosure (T30).

did not find any statistically significant difference in the distribution of frequency of the named dimensions by years of education.

Finally, we found that, at T0, dropout patients less frequently considered Health (Fisher's Exact Test $P = 0.006$) as an important life dimension compared to those with complete follow-up. As this gives a potential for selection bias, we compared T30 with baseline (T0) scores for all patients who had data from these two time points (55 of the 68 patients). As in the full model including patients with complete follow-up ($n = 32$), we found that Health was named

more frequently 30 days after diagnosis disclosure (McNemar test $P < 0.001$). We also performed a similar subanalysis for Job Effectiveness at time point T0 vs. T30, including all 55 patients with data from these two time points. Again, we found a similar result as in the full model with no statistically significant differences in the frequency with which patients nominated Job Effectiveness at these two time points.

Discussion

In the present study, we explored the self-named QoL domains in patients with MS from the onset of symptoms that were suggestive of MS and at three further intervals: immediately after MS diagnosis disclosure and at 1 and 4 years post-diagnosis. The most frequent life domains named by patients were as follows: Family, Work and Finance, Hobbies, Health, Relationship with Friends and Job Effectiveness. The results are consistent with research conducted in patients with MS¹⁶, in patients with other diseases and in healthy adults^{13,21,24}. It is important to note that the labelled domains derived from more specific aspects that could differ between patients. For example, for Family, participants could refer to: 'family support', 'creating my own family', 'parents', etc. (see Appendix A for more detailed data).

The findings also showed that Health and Job Effectiveness changed over time, that is the number of patients reporting these two aspects changed, whereas the majority of named life domains were stable. The Health domain became a critical dimension when patients were made aware of MS diagnosis. In addition, patients tended to be more satisfied with their health after diagnosis disclosure compared to the pre-diagnosis period. This is in line with data concerning the importance of an early disclosure of MS diagnosis for the patients' well-being and QoL^{4,6,9,24,25}. Providing patients with information and clarification about their symptoms reduces uncertainty. It increases the patients' feeling of control and it decreases their level of anxiety and stress, thus improving their overall health satisfaction regardless of any improvement in the symptomatology⁹.

As in previous research on chronic illnesses²⁴, we found that patients with MS tended to be less satisfied with the Health domain compared to the other domains (see Fig. 1), mainly Family, which seems to be the central life domain for MS patients over time.

Job Effectiveness seems to be an important aspect of patients' life until 1 year after diagnosis disclosure, but it tends to become a less crucial domain over time. Specifically, fewer patients indicated Job Effectiveness 4 years after diagnosis disclosure, and in those patients who continued to nominate Job Effectiveness, it became less important than originally perceived.

We are cognizant of a number of limitations of the present study. The results have to be interpreted with caution because of the small sample size and the relatively high dropout rate. The sensitivity analysis showed that the patients with complete follow-up, more often than those with missing data, evaluated Health as more important at baseline. However, when including all 55 patients (81% of the total study population) with data on both baseline and 30 days after diagnosis disclosure, we found similar results as when we included patients with complete follow-up only. These results argue against our findings being entirely caused by selection bias due to the substantial dropout rate. Nevertheless, the number of patients involved is rather limited, and therefore, the study is underpowered to detect smaller differences.

Another limitation is that the low EDSS scores preclude any evaluation of the influence of disability on the estimated associations. Moreover, even the years of education do not seem to shape the dimension that patients indicated as the most important in their lives. The rather homogeneous cultural background of our sample (primarily people from the north of Italy) and the prevalence of women prevent us from determining any potential effect of gender and the region of origin.

In summary, these findings, pertaining to Italian patients with low disability and quite stable disease, suggest that psychological adaptation to chronic diseases with an unpredictable clinical course, such as MS, is mainly character-

ized by a reconceptualization of domains that revolve around oneself, such as professional success, rather than relational domains. Moreover, the changes in significance of QoL domains, although limited, seem to become manifest a few years after diagnosis disclosure.

It is important to note that, in our sample, individuals' neurological disability did not significantly change over time (as shown by the EDSS score) which may be the reason why no other change was observed in named life domains or in the importance and satisfaction rating between the assessments.

It is increasingly evident that knowing all relevant domains of patients' health is a fundamental prerequisite for clinical practice²⁶. Matching medical approaches to patients' priorities, that is, tailoring intervention strategies as much as possible, allows for the most appropriate health-related decisions (e.g. drug choice, risk tolerance, treatment adherence, etc.) and maximizes QoL and health outcomes of patients²⁷⁻²⁹. This is especially relevant in the management of chronic diseases such as MS. Specifically, this study highlights the possibility of basing treatment choice in MS patients on two main domains: personal relationships (i.e. family and friends) and self-efficacy (i.e. work and hobbies). Analysing the way in which these dimensions affect the QoL of MS patients could help health professionals to personalize health management, and thus maximize patients' adherence and the efficacy of all health-related decisions, in order to achieve a better outcome. According to these findings, during the clinical examination, practitioners should investigate patients' goals, standards, expectations, concerns and changes in these aspects over time. Simple questions may be used, for example adaptations of those used in the SEIQoL interview. It is important to note that valuable information can be obtained without significantly affecting the duration of the appointment.

In future studies, it would be interesting to verify whether using these strategies enables practitioners to improve their decision-making regarding patient's care and, alongside this, whether patients' health-care satisfaction can be improved. As patients naming a QoL dimension

by reference to specific aspects may be different for each of them (i.e. family support vs. taking care of family), it would also be of interest to investigate, in future studies, what specifically changes within the stable life area over time. In fact, hypothetically, if a patient answered: 'The relationship with my family: my family is extremely important for me' at the first interview and 'Having family support and understanding' afterwards, these aspects were both categorized as Family even though they could have different meanings for the patient.

In conclusion, giving attention to person-centred aspects other than the clinical symptoms of the disease, such as the domains that patients identify as the most relevant in their life and their alteration over time, may provide practitioners with an important tool in making health-related decisions and possibly altering health-care providers' decisional habits. Moreover, the patient-centred approach contributes to reinforce the therapeutic alliance that is a fundamental prerequisite for medical care adherence and the efficacy of treatments.

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Appendix A The Life dimensions extracted from the SEIQoL, and the specific aspects that constitute these dimensions

Life dimension	Specific aspect (what actually constitutes the life dimensions)	Example (what patient specifically said)
Family	Creating my own family	'The chance to create my own family and have kids'
	Family	'Spending time with my family'
	Family Relationship	'The relationship with my family: my family is extremely important for me'
	Family Support	'Having family support and understanding'
	Family Life at Home	'My life at home with my family'
	Relationship with Parents	'My parents and the relationship with them'
	Relatives	'The relationship with my relatives, my whole family, my sisters, my parents, my grandparents'
	Relatives' Health	'The health of my whole family, I am worried about their health and well-being'
Sharing with Family	'Sharing with my family and spending time together'	
Sister	'My sister and my nephews and nieces'	

Appendix A Continued

Life dimension	Specific aspect (<i>what actually constitutes the life dimensions</i>)	Example (<i>what patient specifically said</i>)
Work/Finance	Job as Economic Independence	'My job gives me economic self-sufficiency, working improves quality of life'; 'My salary and my financial independence'
	Economic Status	'Economic status'
	Job as financial security	'My job means financial security'
	Job to Earn	'My job as the possibility to earn money'; 'To have money'; 'To have a salary'
Hobbies	Money/Money/Salary	
	Animals	'Companionship with my cats'
	Biking	'Biking'
	Cars/Motorbike	'Driving cars especially sports cars'
	Cinema/Movies	'Going to movies'
	Cooking	'Cooking'
	Dancing	'Dancing'
	Embroidering	'Having time and being able to embroider'
	Free Time	'Having free time for my self'
	Gardening	'I am a gardening enthusiast'
	Going Out	'Going out'
	Having Fun	'Having fun'
	Hobby	'My favorite hobbies'
	Holidays/Travelling	'Going on holiday'
	Home Care	'Taking care of my home'
	Massage	'Receiving massage and learning shiatsu massage'
	Music	'Listening to music whenever I can'
	Sport/Physical Activity	'Doing physical activities to improve my physical appearance'; 'Doing sport activities'
	Culture/Arts/Poetry and Theatre	'Culture. Participating in cultural events'; 'Arts make me feel happy'; 'Reading poetry and going to see performances at the theatre'
	Reading	'Reading books'
Swimming	'Swimming'	
Television	'Watching television on my couch'	
Volunteering	'Spending my free time in voluntary work'	
Health	Desire to stay healthy	'I would like to stay healthy to keep on doing what I have to do'
	Disease	'The symptoms bother me'
	Disease Progression	'Hope that the disease does not progress'
	Health	'My health'
	Health and Medical Treatment	'I would like to reach a better health status with some medical treatments'
	Health Information	'Being informed about my health (certainty vs. uncertainty)'
	Physical Health	'Personal physical health'
	Physical Well-being	'My physical well-being and the quality of life'
	Resolve Health Issues	'I would like to resolve my health issues and be well'

Appendix A Continued

Life dimension	Specific aspect (<i>what actually constitutes the life dimensions</i>)	Example (<i>what patient specifically said</i>)
Relationship with friends	Enjoying Friends' Company	'Spending time with friends and enjoying their company'
	Friends	'Having close friends'
	Relationship with Friends and Mutual Respect	'The relationship with my best friends and the respect for each other'
	Having a lot of Acquaintances	'Having a lot of acquaintances and friends'
	Having Friends different from myself	'Socializing with people and friends different from myself'
	Friends' Support	'The presence of friends and their support'
Job effectiveness	Job as Social Relationships	'My job especially because it is the main opportunity to socialize and have friends'
	Ambition	'Job ambition and personal realization'
	Career	'Reaching professional goals in order to get a career advancement'
	Feeling Accepted by Colleagues	'The work environment, my satisfaction and the feeling of being accepted by colleagues'
	Job and Self-Esteem	'My self esteem and my quality of life is affected also by my role at work'
	Job as a passion	'My job is my passion'
	Job as Self-Fulfillment	'My job makes me feel satisfied'
	Job effectiveness	'My job makes me feel important and it distracts me from other problems'
	Professional Acknowledgment	'Having good professional abilities and being acknowledged for that'
	Professional Satisfaction	'Being satisfied at work'
Success at work	'Being successful at work'	