Health-Related Quality of Life of Adults with Childhood Diagnosis of Specific Language Impairment

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Key Words

Specific language impairment · Health-related quality of life · 15D

span. Identification of prognostic factors and a prolonged follow-up of SLI patients could improve the QoL of these patients.

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Abstract

Objective: The health-related quality of life (HRQoL) of adults with childhood diagnosis of specific language impairment (SLI) was evaluated. **Patients and Methods:** Fifty-two patients with a childhood diagnosis of SLI were asked to fill out the 15D-HRQoL questionnaire. The patients were selected from a hospital setting from psychological examination reports showing a below-average verbal intelligence quotient (VIQ) and a normal performance intelligence quotient (PIQ). The 15D was completed adequately by 33 patients (response rate 63.5%). The results were compared with those of age- and gender-matched controls. **Results:** The total 15D score of the study group was lower than that of population controls, but the difference was not statistically significant. The study group performed significantly worse on the dimensions of speech, usual activities, mental function and distress. Gender or PIQ in childhood was not correlated with the 15D scores or dimension scores in adulthood. Childhood VIQ was associated with the dimensions of mental function ($p < 0.01$) and usual activities ($p < 0.05$). **Conclusion:** Our results support earlier findings that SLI affects the entire life

Introduction

Specific language impairment (SLI) is a developmental disorder that persists through life in one form or another [1, 2]. In clinical practice, the diagnosis is based on specific language features, subaverage language functioning, a normal nonverbal level on psychological tests, and exclusion of any other known disorder or disease that could hinder the normal development of language abilities.

Language difficulties have been shown to persist in many follow-up studies [2–5] and the way these difficulties appear varies. Adults with a childhood diagnosis of SLI had difficulties in studying at school, completed fewer years of formal education, and had jobs considered semiskilled or unskilled [6]. They had significant deficits in theory of mind and verbal short-term memory and phonological processing, substantial social adaptation difficulties, and an increased risk of psychiatric disorder [5]. The psychiatric outcome of a group of young SLI

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adults was examined by Beitchman et al. [7]. Language-impaired subjects had significantly more anxiety disorders, especially social phobia, than the controls. Males from the language-impaired group had higher rates of antisocial personality disorder than males from the control group.

During recent years an increasing interest has emerged in studies of health-related quality of life (HRQoL) in patients with various somatic diseases due to demands for evidence-based and cost-effective practices. By contrast, quality of life (QoL) research in developmental medicine has been rare. Records et al. [8] investigated the QoL of 29 young adults with a history of SLI and 29 controls. Subjects were aged 17–25 years. The measurement tool was developed to collect information on various life domains, personal happiness, and life satisfaction. The results indicated no significant differences in QoL between patients and controls. The groups did, however, differ in employment status and in educational status.

Persisting language problems often lead to impaired communication and learning skills, thus affecting the lives of patients in many ways. We were interested in investigating the effects of SLI long after childhood, when formal education had been completed and independent phase of life had been ongoing for some time (if ever started). Support in SLI is offered in childhood, but the persisting problems in adulthood are often ignored. The aims of this study were (1) to measure HRQoL in adults with a childhood diagnosis of severe receptive or receptive/expressive SLI, (2) to compare the results of HRQoL measurement with 'normal' population values, and (3) to determine any association between severity of childhood SLI, as assessed by psychological tests, and the present status of HRQoL and its dimensions.

Patients and Methods

Patients

The patients were selected from the records of psychological examinations performed during 1970–1986 in our department on language-impaired children with severe language disorders caused by various etiologies. Based on the Wechsler Intelligence Scale (WISC), which had been taken into clinical practice gradually in the 1970s, first with selected patients and later with virtually all patients examined in our ward, we selected individuals who fulfilled the criteria of normal nonverbal intelligence and subnormal verbal performance. The verbal subtests consist of: (1) information that includes questions on general knowledge, (2) similarities, which demands the understanding of how two concepts are alike, (3) arithmetics that includes arithmetic questions and concepts, (4) vocabulary that measures the ability to

explain the meaning of words and (5) comprehension, which is the ability to understand social situations and common concepts. The results from examinations of speech and language pathologists were not attainable for this study. Patients with gross neurological deficit or hearing impairment were excluded. Altogether 56 patients met the inclusion criteria. While sending the questionnaires, we found that 1 patient had died, 1 had moved out of the country, and 2 patients had no registered address. The total number of patients in this study was therefore 52.

Psychological Examination Records

The total verbal intelligence scores (VIQ) and performance intelligence scores (PIQ) were obtained from the psychological examination records. Any information on speech was also collected from the psychologist's records and coded in the data as follows: 1 = phonological difficulties, 2 = articulation errors and 3 = tendency to mutistic behavior. Naming difficulty is placed in its own category.

Health-Related Quality of Life

Patients' HRQoL was measured with a 15D questionnaire [9–12]. A generic (i.e., not disease-specific) HRQoL questionnaire was chosen, because we were interested in how adults with a history of SLI manage compared to the population in general, not only in those areas of everyday functioning that are supposedly deteriorated in language-impaired individuals. The 15D subscribes to the definition of health by the World Health Organisation as being composed of physical, mental and social well-being [12]. The English version of the 15D questionnaire is included in the Appendix. 15D is a generic, multidimensional, standardized, sensitive, self-administered measure of HRQoL. It has 15 dimensions (breathing, mental function, speech, vision, mobility, usual activities, vitality, hearing, eating, elimination, sleeping, distress, discomfort and symptoms, sexual activity, depression) each divided into 5 levels (best level = 1, worst level = 5). It is easy to use and is completed in 5–10 min. Proxy administration can also be used. 15D is applicable both as a profile and a single index measure. The single index (15D score) covering all dimensions is calculated using a set of utility or preference weights elicited from the general public through a three-stage valuation procedure [12]. The maximum score is 1 (no problems on any dimension) and the minimum score 0 (equal to being dead). 15D has been demonstrated to compare favorably with other HRQoL measures [13, 14]. Agreement between a generic (15D) and a disease-specific QoL instrument has also been found [15, 16].

Population Data

The general Finnish population data for HRQoL were obtained from the Health 2000 Health Examination Survey, which included the 15D questionnaire [17]. In the Health 2000 survey a nationally representative sample of 10,000 persons was drawn from the population aged 18 and over. The age- and gender-matched controls for this study consist of 1,915 persons of the initial sample.

Statistical Analysis

Data were analyzed using SPSS for Windows, version 12.0.1 statistical software (SPSS Inc., Chicago, Ill., USA). Descriptive statistics were used to describe the demographic characteristics. Comparative analysis of demographic characteristics between re-

Table 1. Descriptive characteristics of the study group

Characteristics	Respondents (n = 33) ^a	Nonrespondents (n = 19)
Gender**		
Male	25 (76%)	16 (84%)
Female	8 (24%)	3 (16%)
Age*		
Mean $\pm$ SD	34.46 $\pm$ 4.75	31.49 $\pm$ 4.29
Range	27.0 – 43.3	26.0 – 40.2
Age at psychological testing		
Mean $\pm$ SD	7.14 $\pm$ 0.83	6.84 $\pm$ 0.69
Range	6.0 – 9.0	6.1 – 8.0
PIQ		
Mean $\pm$ SD	103.00 $\pm$ 9.96	100.95 $\pm$ 9.86
Range	90 – 125	84 – 121
VIQ		
Mean $\pm$ SD	76.26 $\pm$ 10.24	75.89 $\pm$ 8.20
Range	49 – 89	60 – 86
Speech code total	16 (48%)	6 (31%)
Phonology disorder	9 (27%)	3 (16%)
Articulation errors	4 (12%)	1 (5%)
Tendency to mutism	3 (9%)	2 (11%)
Naming difficulties	5 (15%)	2 (11%)

Speech code and naming difficulties as reported in psychological examinations. * $p < 0.05$, ** $p < 0.01$.

^a n = 31 in VIQ.

spondents and nonrespondents was performed using an independent samples t test (two-tailed) and the χ^2 -test for gender.

The Mann-Whitney U test was used to compare the 15D score of patients and population controls. An independent samples t test (two-tailed) and Wilcoxon's test were applied when comparing mean group scores between the patients and population controls.

The associations between respondent characteristics, the 15D score, and each dimension were measured using Spearman's rank correlation coefficients.

Ethical Consideration

The study design was approved by the Ethical Committee of Ophthalmology, Otorhinolaryngology, Neurology and Neurosurgery of the Helsinki and Uusimaa Hospital Group (45/2003). Patients gave their written consent and returned it by mail with the questionnaire.

Results

Of the 52 patients eligible for the study, 35 returned the questionnaires. Two of the 15D questionnaires lacked more than three answers and were dropped to the nonre-

spondent group. In 2 cases, the question about sexual activity (Appendix, question 15) was not answered, and consequently, the values were predicted using the responses to the other dimensions, and age and gender as explanatory variables [9]. Thus, the total number of respondents in this study was 33 and the response rate 63.5%. Those who did not return the questionnaire were sent a maximum of two reminders; however, most of the answers were received after the first mailing. There was a note of proxy administration used in 9 cases, not used in 19 cases, and the note was missing in 5 cases. Every fourth respondent used proxy administration, which was probably mostly due to difficulties in reading because of SLI. The number of age- and gender-matched population controls from the survey was 1,915.

Gender distribution, average age, and age at the time of psychological testing, as well as reported PIQ and VIQ scores, speech code, and naming difficulties of the respondents and nonrespondents are presented in table 1. No significant differences existed between the groups regarding average age at psychological testing, PIQ, or VIQ. Verbal subtests included tests on information, similarities, arithmetics, vocabulary and comprehension and the mean subtest scores of the study group for the named tests were 5.90, 7.68, 4.83, 7.08, and 7.34, respectively. A score of 7 standard points is considered to be poor normal. There was no statistically significant difference between the respondents and nonrespondents in the subtest scores. VIQ results were lacking for 2 patients in the respondent group; no verbal tests were made at that time, but there was a notation of subnormal language performance from a previous control. A slight, although significant, difference was present between respondents and nonrespondents regarding the age at the time of the study and gender.

The psychologist reported difficulties in speech in 20 respondents (61%) and 8 nonrespondents (42%). One respondent had had both naming difficulties and articulation errors. The differences in speech code and in naming between respondents and nonrespondents did not reach statistical significance.

The difference in the total 15D score of patients (0.920) and age- and gender-matched controls (0.950) was 0.03. Although this did not reach statistical significance, it was at a level that has been considered to be of clinical significance in earlier studies [18]. The total 15D scores and levels of each dimension for patients and the population sample are shown in figure 1. Significant differences were found on the dimensions of speech, usual activities, mental function, and distress (Appendix, questions 7, 9, 10,

Fig. 1. HRQoL of the study group and the population controls measured by the 15D questionnaire. Significant differences were found on the dimensions of speech, usual activities, mental function and distress using independent samples t test. * $p < 0.05$, ** $p < 0.01$.

Table 2. Distribution of levels (1–5) in respondents of the study group ($n = 33$) and the population controls ($n = 1,915$) on dimensions of speech, usual activities, mental function and distress in the 15D questionnaire

Dimension	Level 1	Level 2	Level 3	Level 4	Level 5
Speech**					
Study group	66.7	27.2	–	6.0	–
Population controls	95.8	4.0	0.2	0.1	–
Usual activities*					
Study group	75.8	18.2	6.0	–	–
Population controls	92.9	6.0	0.7	0.3	0.1
Mental function*					
Study group	69.7	27.2	3.0	–	–
Population controls	89.6	9.9	0.4	0.0	0.0
Distress*					
Study group	51.5	39.4	6.0	3.0	–
Population controls	75.3	21.9	1.8	0.7	0.4

Best level is 1, worst level is 5. The numbers are percentages. On all these dimensions there was a significant difference between the groups (* $p < 0.05$, ** $p < 0.01$) measured with independent samples t test (two-tailed).

13). On all of these dimensions, patients were worse off than controls. The distribution of the values of the study group and population control group on the dimensions of speech, usual activities, mental functioning, and distress is presented in table 2. The majority of the respondents had chosen level 1 (best level) on these dimensions, but almost half felt at least slightly distressed at the time of the study, and one third had difficulties in speech, performing usual activities, and thinking clearly and logically (mental function), with moderate or severe difficulties (levels 3 and 4) experienced by 1–4 patients on each dimension.

A low VIQ measured in childhood was correlated with choosing levels 2–4 rather than 1 (being normal) on dimensions of usual activities (significance set at a $p < 0.05$) and mental function (significance set at a $p < 0.01$). The VIQ in childhood was not correlated with the total 15D score or any of the other dimensions of 15D. Nor did childhood PIQ correlate with either of these. Thus, high PIQ does not protect against having deteriorated HRQoL, whereas low VIQ seems to make one vulnerable to such effects.

In childhood, 20 patients in the respondent group had had speech difficulties recorded in psychological test reports. Of these 20 patients, 9 felt that they still had speech difficulties while filling out the 15D questionnaire. Of the 9 respondents who reported experiencing slight difficulties (level 2) in speech, 2 had a history of tendency to mutism, 2 had articulation errors, 3 had naming difficulties, and 2 had no psychologist-reported speech problems at the time of testing. Of the 2 respondents who felt that people had difficulties in understanding their speech (level 4), 1 had a history of phonological difficulties and the other a tendency to mutistic behavior.

Discussion

We explored how language-impaired children cope later in life from their own viewpoint as compared with their age- and gender-matched peers. This was studied by the 15D HRQoL questionnaire, which is easy to fill out and has good reliability and stability. As health is considered an important factor in personal well-being, the 15D results represent, in our opinion, well the overall situation of a former SLI patient at the time of the measurement. The patients were gathered from a clinical setting and represent a sample of those SLI patients whose language impairment required hospitalization for a period (or periods) of time. The reason for staying at a hospital

ward varied from lack of speech therapists in the countryside and need of intensive rehabilitation to problems in testing the child in an ambulatory setting. The patients selected for this study showed normal nonverbal intelligence but severe difficulties in verbal subtests of WISC. In real life and clinical practice such strict selection criteria are seldom possible, and thus, our clinical diagnosis is also based on other data such as speech therapists' tests and use of language in various real-life situations. Taken together, the study group represents SLI patients with at least moderate, but mostly severe receptive language impairment in childhood.

The response rate in the study was 63.5%, which is satisfactory, but not good. The motivation to take part in the study was probably most dependent on the information given about the study, the overall life situation of the respondent and also the self-experienced difficulties, since there were no financial or other benefits offered to the participants. The childhood performance did not differentiate respondents from nonrespondents, but the nonrespondents were somewhat younger and more likely to be of male gender. A questionnaire, which requires reading and understanding, is not an ideal way to gather information from language-impaired individuals. However, proxy administration was possible and was used in 9 cases (27%). The high number of proxies was probably due to reading difficulties since the patients were relatively young, had normal vision according to the questionnaire (Appendix, question 2), and had at least had normal nonverbal intellectual capacity. Using proxies makes it possible also for individuals with such difficulties to take part in this kind of a study. Age at the time of the psychological testing did not differ significantly between respondents and nonrespondents. The respondent group contained more females (25%) than the nonrespondent group (16%). The proportion of females in the respondent group is close to the gender distribution observed in our clinic and in several follow-up studies [1, 3, 4, 8]. In a prevalence study by Tomblin et al. [19], the gender distribution in SLI-diagnosed children was 59% males and 41% females. Because the population sample was age- and gender-matched, differences in gender and age of respondents and nonrespondents have no effect on the comparison of the respondent group and population controls.

The total 15D score of the study group did not differ significantly from the population values, although it was 0.03 lower than that of the population controls. A difference of 0.03 was, however, considered to be clinically relevant in a follow-up of HRQoL [18]. Because deficient language is not thought to cause physical restrictions or

to increase the risk of somatic diseases, the differences in most dimensions measured are small, as can be seen in figure 1. The reason for the good total 15D score can also indicate sufficient support and acceptance from the immediate environment. Deficient language affects communication, schooling, and social relationships and increases the risk of psychiatric disorders even in adulthood [5–7]. In our study group, the dimensions that measured speech, usual activities, mental state and distress (Appendix, questions 7, 9, 10, 13) differed significantly from the population values. Records et al. [8] reported that the patients with a history of SLI did not differ from controls in personal happiness and life satisfaction. Their participants were, however, clearly younger than ours (17–25 vs. 27–43 years); life satisfaction in former SLI patients may decrease with age and the continuing problems in communication, or our participants may have had more severe language problems all in all.

The persisting problems in speech are in concordance with several earlier studies [1–4]. In the 15D questionnaire, the values and ratings of speech (Appendix, question 7) were not designed specifically for the language-impaired, but the overall rating seems reasonable. In our study, 22 respondents (67%) did not experience any speech problems (level 1), 9 (27%) had minor difficulties (level 2) and 2 (6%) felt that other people had difficulty in understanding them (level 4). In population controls, 95.8% had chosen level 1 (table 2). The reported difficulties in the study group were manifold as compared with the general population. In childhood, 20 patients in the respondent group had had speech difficulties of some kind, and of these 9 felt that they continued to have speech difficulties in adulthood. Personal demands for quality of speech certainly vary markedly, but SLI patients with mainly receptive language problems are at risk of continuing difficulty in expressing themselves verbally, although the majority have no self-estimated problems in speech.

The values on the dimensions of usual activities (Appendix, question 9) and mental functioning (Appendix, question 10) were significantly worse in the study group than in the population sample. This could indicate lower educational and employment status, as reported in some studies [6, 8], as well as problems in social adaptation and interaction and continued language and literacy difficulties. In a study by Felsenfeld et al. [6], SLI patients had more difficulties in school and completed fewer years of formal education than controls. Language-impaired individuals also more often had jobs considered semiskilled

or unskilled than controls or gender-matched siblings. In another study of adults with a history of SLI, the employment rate was lower in patients than in controls [8]. In a follow-up of children with developmental receptive language disorders, Howlin et al. [20] showed that many subjects still lived with their parents at an average age of 23–24 years, few had close friends or permanent jobs, and ratings of social interaction indicated abnormalities in a number of different areas. Clegg et al. [5] conducted 30-year follow-up of 17 males with a childhood diagnosis of severe developmental language disorder. The language disorder persisted into adulthood; subjects had significant deficits in theory of mind, verbal short-term memory, and phonological processing as well as substantial social adaptation difficulties and an increased risk of a psychiatric disorder. Many follow-up studies end in late adolescence or early adulthood [3, 4, 7]. Lewis and Freebairn [3] followed up children with preschool phonology disorders and reported that a subgroup with both phonology and language disorders had more difficulties in reading and spelling in early adulthood than those with phonology problems alone. In evaluating young adults with and without speech/language impairments, Johnson et al. [4] found high rates of continued communication difficulties in the impaired, considerable stability in language performance over time, and worse long-term outcomes in initial language impairments than in speech impairments. The psychiatric outcome of the same group of young adults was examined by Beitchman et al. [7]. Language-impaired individuals had significantly more anxiety disorders, especially social phobia, than controls. Males in the language-impaired group had higher rates of antisocial personality disorder than males in the control group.

Almost half of our study population felt at least some distress or were strained or nervous (Appendix, question 13). Two individuals were moderately distressed (level 3) and 1 very distressed (level 4). Distress can result from various conditions and situations. Even in the population group, the feelings of distress were reported by 25%. In distressed former SLI patients the role of language impairment and its consequences should be taken seriously.

As already discussed, subjects with a history of SLI often remain disabled in one way or another. In Finland, clinical follow-up generally ends in the early school years; only on rare occasions, depending on the resources, is it continued until the end of secondary school. Special schools and classes give academic support and advice on further studies. Other types of support in maintaining learned skills, strengthening social adaptation and inter-

action, and facilitating communication should be available when needed, even in adulthood. Adults with a childhood diagnosis of SLI are often unaware of their underlying difficulties, which can at least in part explain their feelings of distress and problems in usual activities. It is our responsibility to ensure the continued support for SLI patients.

In conclusion, our findings indicate that the majority of adults with a childhood diagnosis of moderate to severe receptive SLI have a good HRQoL. Verbal intelligence tests have moderate value in predicting which individuals are at risk of an impaired HRQoL, at least on some dimensions, whereas PIQ is less predictive. The challenge of everyday practice is to detect SLI children with persisting difficulties or risk of deteriorated life quality in adulthood on any dimension, paying particular attention to speech, usual activities, mental function, and distress. These children and their families need prolonged follow-up and support in adult life.

Appendix: Quality of Life Questionnaire (15D®)

Please read through all the alternative responses to each question before placing a cross against the alternative which best describes your present health status. Continue through all 15 questions in this manner, giving only one answer to each.

Question 1: Mobility

- 1 ☐ I am able to walk normally (without difficulty) indoors, outdoors and on stairs
- 2 ☐ I am able to walk without difficulty indoors, but outdoors and/or on stairs I have slight difficulties
- 3 ☐ I am able to walk without help indoors (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others
- 4 ☐ I am able to walk indoors only with help from others
- 5 ☐ I am completely bed-ridden and unable to move about

Question 2: Vision

- 1 ☐ I see normally, i.e. I can read newspapers and TV text without difficulty (with or without glasses)
- 2 ☐ I can read papers and/or TV text with slight difficulty (with or without glasses)
- 3 ☐ I can read papers and/or TV text with considerable difficulty (with or without glasses)
- 4 ☐ I cannot read papers or TV text either with glasses or without, but I can see enough to walk about without guidance
- 5 ☐ I cannot see enough to walk about without a guide, i.e. I am almost or completely blind

Question 3: Hearing

- 1 ☐ I can hear normally, i.e. normal speech (with or without a hearing aid)
- 2 ☐ I hear normal speech with a little difficulty
- 3 ☐ I hear normal speech with considerable difficulty; in conversation I need voices to be louder than normal
- 4 ☐ I hear even loud voices poorly; I am almost deaf
- 5 ☐ I am completely deaf

Question 4: Breathing

- 1 ☐ I am able to breathe normally, i.e. with no shortness of breath or other breathing difficulty
- 2 ☐ I have shortness of breath during heavy work or sports, or when walking briskly on flat ground or slightly uphill
- 3 ☐ I have shortness of breath when walking on flat ground at the same speed as others my age
- 4 ☐ I get shortness of breath even after light activity, e.g. washing or dressing myself
- 5 ☐ I have breathing difficulties almost all the time, even when resting

Question 5: Sleeping

- 1 ☐ I am able to sleep normally, i.e. I have no problems with sleeping
- 2 ☐ I have slight problems with sleeping, e.g. difficulty in falling asleep, or sometimes waking at night
- 3 ☐ I have moderate problems with sleeping, e.g. disturbed sleep, or feeling I have not slept enough
- 4 ☐ I have great problems with sleeping, e.g. having to use sleeping pills often or routinely, or usually waking at night and/or too early in the morning
- 5 ☐ I suffer severe sleeplessness, e.g. sleep is almost impossible even with full use of sleeping pills, or staying awake most of the night

Question 6: Eating

- 1 ☐ I am able to eat normally, i.e. with no help from others
- 2 ☐ I am able to eat by myself with minor difficulty (e.g. slowly, clumsily, shakily, or with special appliances)
- 3 ☐ I need some help from another person in eating
- 4 ☐ I am unable to eat by myself at all, so I must be fed by another person
- 5 ☐ I am unable to eat at all, so I am fed either by tube or intravenously

Question 7: Speech

- 1 ☐ I am able to speak normally, i.e. clearly, audibly and fluently
- 2 ☐ I have slight speech difficulties, e.g. occasional fumbling for words, mumbling, or changes of pitch
- 3 ☐ I can make myself understood, but my speech is e.g. disjointed, faltering, stuttering or stammering
- 4 ☐ Most people have great difficulty understanding my speech
- 5 ☐ I can only make myself understood by gestures

Question 8: Elimination

- 1 ☐ My bladder and bowel work normally and without problems
- 2 ☐ I have slight problems with my bladder and/or bowel function, e.g. difficulties with urination, or loose or hard bowels
- 3 ☐ I have marked problems with my bladder and/or bowel function, e.g. occasional 'accidents', or severe constipation or diarrhea
- 4 ☐ I have serious problems with my bladder and/or bowel function, e.g. routine 'accidents', or need of catheterization or enemas
- 5 ☐ I have no control over my bladder and/or bowel function

Question 9: Usual activities

- 1 ☐ I am able to perform my usual activities (e.g. employment, studying, housework, free-time activities) without difficulty
- 2 ☐ I am able to perform my usual activities slightly less effectively or with minor difficulty
- 3 ☐ I am able to perform my usual activities much less effectively, with considerable difficulty, or not completely
- 4 ☐ I can only manage a small proportion of my previously usual activities
- 5 ☐ I am unable to manage any of my previously usual activities

Question 10: Mental function

- 1 ☐ I am able to think clearly and logically, and my memory functions well
- 2 ☐ I have slight difficulties in thinking clearly and logically, or my memory sometimes fails me
- 3 ☐ I have marked difficulties in thinking clearly and logically, or my memory is somewhat impaired
- 4 ☐ I have great difficulties in thinking clearly and logically, or my memory is seriously impaired
- 5 ☐ I am permanently confused and disoriented in place and time

Question 11: Discomfort and symptoms

- 1 ☐ I have no physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 2 ☐ I have mild physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 3 ☐ I have marked physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 4 ☐ I have severe physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 5 ☐ I have unbearable physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

Question 12: Depression

- 1 ☐ I do not feel at all sad, melancholic or depressed
- 2 ☐ I feel slightly sad, melancholic or depressed
- 3 ☐ I feel moderately sad, melancholic or depressed
- 4 ☐ I feel very sad, melancholic or depressed
- 5 ☐ I feel extremely sad, melancholic or depressed

Question 13: Distress

- 1 ☐ I do not feel at all anxious, stressed or nervous
- 2 ☐ I feel slightly anxious, stressed or nervous
- 3 ☐ I feel moderately anxious, stressed or nervous
- 4 ☐ I feel very anxious, stressed or nervous
- 5 ☐ I feel extremely anxious, stressed or nervous

Question 14: Vitality

- 1 ☐ I feel healthy and energetic
- 2 ☐ I feel slightly weary, tired or feeble
- 3 ☐ I feel moderately weary, tired or feeble
- 4 ☐ I feel very weary, tired or feeble, almost exhausted
- 5 ☐ I feel extremely weary, tired or feeble, totally exhausted

Question 15: Sexual activity

- 1 ☐ My state of health has no adverse effect on my sexual activity
- 2 ☐ My state of health has a slight effect on my sexual activity
- 3 ☐ My state of health has a considerable effect on my sexual activity
- 4 ☐ My state of health makes sexual activity almost impossible
- 5 ☐ My state of health makes sexual activity impossible

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References

- 1 Tomblin JB, Freese PR, Records NL: Diagnosing specific language impairment in adults for the purpose of pedigree analysis. *J Speech Hear Res* 1992;35:832–843.
- 2 Felsenfeld S, Broen PA, McGue M: A 28-year follow-up of adults with a history of moderate phonological disorder: linguistic and personality results. *J Speech Hear Res* 1992; 35:1114–1125.
- 3 Lewis BA, Freebairn L: Residual effects of preschool phonology disorders in grade school, adolescence, and adulthood. *J Speech Hear Res* 1992;35:819–831.
- 4 Johnson CJ, Beitchman JH, Young A, Escobar M, Atkinson L, Wilson B, Browlie EB, Douglas L, Taback N, Lam I, Wang M: Fourteen-year follow-up of children with and without speech/language impairments: speech and language outcomes. *J Speech Lang Hear Res* 1999;42:744–760.

- 5 Clegg J, Hollis C, Mawhood I, Rutter M: Developmental language disorders – a follow-up in later adult life: cognitive, language and psychosocial outcomes. *J Child Psychol Psychiatry* 2005;46:128–149.
- 6 Felsenfeld S, Broen PA, McGue M: A 28-year follow-up of adults with a history of moderate phonological disorder: educational and occupational results. *J Speech Hear Res* 1994; 37:1341–1353.
- 7 Beitchman, JH, Wilson B, Johnson CJ, Atkinson L, Young A, Adlaf E, Escobar M, Douglas L: Fourteen-year follow-up of speech/language-impaired and control children: psychiatric outcome. *J Am Acad Child Adolesc Psychiatry* 2001;40:75–82.
- 8 Records NL, Tomblin JB, Freese PR: The quality of life of young adults with histories of specific language impairment. *Am J Speech Lang Pathol* 1992;1:44–50.
- 9 Sintonen H: Properties of the health state descriptive system. <http://www.15d-instrument.net/service>.
- 10 Sintonen H: The 15D-measure of health-related quality of life. I. Reliability, validity, and sensitivity of its health state descriptive system. Working Paper 41. Melbourne, National Center for Health Program Evaluation, 1994. <http://www.buseco.monash.edu.au/centres/che/publications.php#1994>.
- 11 Sintonen H: The 15D-measure of health-related quality of life. II. Feasibility, reliability, and validity of its valuation system. Working Paper 42. Melbourne, National Center for Health Program Evaluation, 1995. <http://www.buseco.monash.edu.au/centres/che/publications.php#1994>.
- 12 Sintonen H: The 15D instrument of health-related quality of life: properties and applications. *Ann Med* 2001;33:328–336.
- 13 Stavem K: Reliability, validity and responsiveness of two multiattribute utility measures in patients with chronic obstructive pulmonary disease. *Qual Life Res* 1999;8: 45–54.
- 14 Hawthorne GRJ, Richardson J, Day NA: A comparison of the assessment of quality of life (AQoL) with four other generic utility instruments. *Ann Med* 2001;33:358–370.
- 15 Kauppinen R, Rissanen P, Sintonen H: Agreement between a generic and a specific quality-of-life instrument: the 15D and SGRQ in asthmatic patients. *Qual Life Res* 2000;9:997–1003.
- 16 Haapaniemi TH, Sotaniemi KA, Sintonen H, Taimela E for the EcoPD Study Group: The generic 15D instrument is valid and feasible for measuring health related quality of life in Parkinson's disease. *J Neurol Neurosurg Psychiatry* 2004;75:976–983.
- 17 Aromaa A, Koskinen S: Health and functional capacity in Finland: baseline results of the Health 2000 Health Examination Survey. Publications of National Public Health Institute 2004, Series B 12/2004, p 171.
- 18 Sintonen H: Outcome measurement in acid-related diseases. *Pharmacoeconomics* 1994; 5(suppl 3):17–26.
- 19 Tomblin JB, Records NL, Buckwalter P, Zhang X, Smith E, O'Brian M: Prevalence of specific language impairment in kindergarten children. *J Speech Lang Hear Res* 1997; 40:1245–1260.
- 20 Howlin P, Mawhood L, Rutter M: Autism and developmental receptive language disorder: a follow-up comparison in early adult life II: social, behavioural and psychiatric outcomes. *J Child Psychol Psychiatry* 2000; 41:561–587.