Living with Dysarthria: Evaluation of a Self-Report Questionnaire

Lena Hartelius Marie Elmgren Rebecca Holm Ann-Sofie Lövgren
Stiliani Nikolaidis

Institute of Neuroscience and Physiology, Division of Speech and Language Pathology, and the Vårdal Institute,
Göteborg University, Göteborg, Sweden

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Abstract

The study describes an effort to evaluate the speech difficulties as perceived by individuals with dysarthria. A self-report questionnaire, Living with Neurologically Based Speech Difficulties (Living with Dysarthria), was answered by 55 individuals with varying types and degrees of dysarthria. Results show that both type and degree of subjectively perceived communicative difficulties varied. Degree of communicative difficulties was not related to age, gender, diagnosis, disease duration or employment status in this group. Generally, the overriding problems were related to restrictions in communicative participation, possibilities to actively take part in work and studies and to express one's personality were particularly affected. Communication was also affected by emotions and by the number and familiarity of people present in communicative encounters. The dominating speech difficulties were related to reduced speech rate and a need for repetition as a consequence of misunderstandings. A statistically nonsignificant difference was found between the higher mean of the group with moderate dysarthria compared to the groups with severe and mild dysarthria, indicating that severity of dysarthria does not necessarily predict extent of perceived communicative difficulties. It is concluded that systematic subjective reports should always be included in the assessment of individuals with acquired dysarthria.

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Introduction

Some aspects of a neurogenic speech disorder are overt and easier to identify than others. Speech and voice parameters can be assessed and quantified in terms of number of seconds of sustained phonation, number of syllables per second in an alternating motion rate task, percentage intelligible words, etc. The covert aspects, the subjective consequences of living with a speech disorder caused by a neurological condition, are more complex and difficult to get a comprehensive picture of. Encountering speech difficulties due to a neurological disease or injury may involve great problems. This paper presents an effort to evaluate speech difficulties as perceived by individuals with dysarthria using the Living with Dysarthria (LwD) questionnaire. It also attempts to determine whether this clinically relevant short questionnaire achieves similar results compared to the longer Communication Profile for Speakers with Motor Speech Disorders.

Dysarthria is defined as a neurological motor speech disorder characterized by slow, weak, imprecise and/or uncoordinated movements of the speech musculature [1]. Acquired dysarthria can be classified as progressive (as in degenerative diseases such as Parkinson's disease, multiple sclerosis, motor neuron disease, Huntington's disease, etc.) or nonprogressive (as in stroke or traumatic brain injury). Dysarthria is often categorized in perceptually based types [2–3] and/or according to degree of dysarthria (mild, moderate or severe) [4].

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Lena Hartelius
Sahlgrenska Academy at Göteborg University, Institute of Neuroscience and
Physiology, Division of Speech and Language Pathology
Hälsövetenskapligt Centrum, Box 452, SE-405 30 Göteborg (Sweden)
Tel. +46 31 773 6884, Fax +46 31 82 34 15, E-Mail lena.hartelius@neuro.gu.se

In recent years, the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [5] have been used as a conceptual framework and basis for classification of speech and language disorders. The structure of ICF allows any health condition to be classified in terms of body structure or function, activity and participation, and any disability to be classified as an impairment of body structure or function, activity limitation and participation restriction. Also, the biopsychosocial model of ICF includes the impact of contextual (environmental and personal) factors on activity and participation. Personal factors include age, education, other health conditions, coping styles, etc. Environmental factors include products, technology, natural environment but also attitudes, support and relationships. Today, the classification has been applied to a number of communicative disorders, but Yorkston et al. [6] applied the constructs to dysarthria as a chronic condition as early as 1988. Considerable research efforts have been put into the development of assessment methods to capture the different aspects of communicative structural/functional impairment, activity limitation and participation restriction caused by dysarthria. Impairment of structure and/or function is often more easily assessed and measured compared to the other levels. One example of a structural/functional symptom of dysarthria is velopharyngeal insufficiency, causing hypernasality, which can be measured using instrumental and clinical methods. Communicative activity can be assessed in terms of intelligibility, speaking rate, naturalness and depends in part on inclusion of a second person, a listener. Restrictions in communicative participation need to be evaluated primarily by the person with dysarthria, in order to reflect the true nature of the problem. The importance of the insider's perspective in obtaining a correct and comprehensive picture of limitations in communicative abilities caused by dysarthria has been emphasized by Yorkston et al. [7] and can be explored using both qualitative and quantitative methods, in interviews or self-report questionnaires.

A few attempts have been made, to describe subjective communication problems using self-report questionnaires intended for individuals with dysarthria. Berry and Sanders [8] developed a Situation Intelligibility Survey, an evaluation protocol intended for the patient and/or primary listeners in the patient's environment. Up to 25 different situations can be scored according to how often the patient has difficulty or is difficult to understand in that situation. The protocol can help clinicians identify situations where the patient or others in the en-

vironment might need specific instruction or support to enhance intelligibility.

Lubinski [9] listed a number of probe questions for patients with dysarthria. The questions were designed to elicit information about how the person defines the communication problem and its impact on different aspects of his or her life. Questions concerning motivation to improve were also included. A corresponding set of questions was posed to family members concerning demands, resources and definition of the problem.

In 1997, Sullivan, Beukelman, and Gaebler developed an assessment protocol of communicative effectiveness by social context. The effectiveness in each selected context can be rated on a seven-point equal-appearing interval scale. The protocol was first described in Yorkston et al. [1] and has been used to examine the relationship between speech intelligibility and communication effectiveness in 25 individuals with amyotrophic lateral sclerosis (ALS) and their primary listeners [10]. Results of this study show that perceptions of communication effectiveness across the 10 different social situations were quite similar for individuals with ALS and their listeners. It was also noted that there was a significant positive relationship between intelligibility of speech and self-perceived ratings of communication effectiveness.

The three questionnaires mentioned above are intended for use in daily clinical practice as a basis for clinical intervention to enhance functional communication. In order to get a more comprehensive picture of dysarthria from the viewpoint of individuals with dysarthria, Yorkston and Bombardier [11] developed their Communication Profile for Speakers with Motor Speech Disorders. This self-report questionnaire has been used in a number of research projects and consists of 100 statements concerning perceived characteristics of the disorder, situational difficulty, compensatory strategies used, and perceived reactions of others. The person is asked to agree or disagree with each statement, using a five-point scale. The questionnaire was used in a study of 33 individuals with different types and degrees of dysarthria [12]. The only significant difference found between severity groups was perceived reactions of others. Individuals with severe dysarthria felt that others were more helpful, more solicitous, and more punishing than did individuals with mild or moderate dysarthria.

Antonius, Beukelman and Reid used the Communication Profile in a study of 15 patients with Parkinson's disease and their communication partners [13]. In this study, no significant differences between the individuals with Parkinson's disease and their primary partners were

found for the areas of situational difficulty and perceived reactions of others. However, differences were found in reports of compensatory strategies used, with the dysarthric speakers reporting that they used improved precision and partner instruction to a higher degree than reported by their partners. Also, the number of dysarthric characteristics endorsed was higher in the group of individuals with Parkinson's disease compared to their partners' reports. The questionnaire was also used to evaluate the results of group therapy with 6 patients with Parkinson's disease [14]. Intervention focused on improving speech intelligibility using functional communication strategies and was evaluated with measures of intelligibility, perceptual assessments and communicative effectiveness (including the Communication Profile). Five of the 6 participants were considered to have improved their speech performance, but there seemed to be no apparent relationship between the benefit in terms of increased intelligibility and self-reported communicative difficulties.

The Communication Profile for Speakers with Motor Speech Disorders has been translated into Swedish and was used as one of the outcome measures to evaluate the treatment of a group of 15 patients with hypokinetic dysarthria and Parkinson's disease [15]. As a result of treatment focusing on vocal efficiency and prosody, all perceived situational difficulties were significantly reduced. No differences in compensatory strategies, speech characteristics or reactions of others were noted after therapy.

In summary, efforts have been made to develop assessment methods to capture different aspects of communicative structural/functional impairment, activity limitation and participation restriction caused by dysarthria. Previous studies indicate that what the individual speaker with dysarthria perceives as problematic might and might not be related to speech intelligibility, severity of dysarthria and the perceptions of significant others. It is obvious that the impact of dysarthria on a person's life is subjective. Consequently, the insider's perspective is an essential addition to the assessment of dysarthria. The self-report questionnaire used in the present study, *Living with Neurologically Based Speech Difficulties*, was developed to capture the essence of individual problems without being too extensive. The questionnaire is intended for use in a clinical setting, and it was considered important that it could be administered in a reasonably short time. The aim of the study was to describe the perceived difficulties of 55 individuals with dysarthria. The specific questions asked were:

- How do the overall ratings on the *Living with Neurologically Based Speech Difficulties* relate to age, gender, diagnosis, disease duration, duration and degree of dysarthria, education and degree of professional activity in this group?
- Is the information gained from *Living with Neurologically Based Speech Difficulties* comparable to information received from an equivalent but more extensive instrument, the *Communication Profile for Individuals with Motor Speech Disorders* [12]?

Methods

Questionnaires

The self-report questionnaire *Living with Neurologically Based Speech Difficulties* (or *LwD*) has been developed within the Vårdal Institute and its research platform of chronically ill and disabled young adults (www.vardalinstitutet.net). The aim is to find out how these individuals perceive themselves and their speech difficulties, as well as how they adjust to their situation.

The selection of questionnaire items was based first of all on a careful review of published and unpublished scales and questionnaires directed towards individuals with speech and language disorders. Secondly, an interview study of 18 individuals with multiple sclerosis, focusing on the experiences of communication and communicative barriers and strategies perceived in daily life with a long-standing chronic disease also generated ideas on important issues to include [16].

Part A includes a number of general questions concerning age, gender, type of disease or injury (stroke, neurological disease, traumatic brain injury or other), disease duration, duration of speech difficulties, type and extent of education and employment. Part B comprises 50 statements divided into ten different sections. Section 1 includes statements regarding how communication is influenced by problems related to speech, section 2 to language/cognition and section 3 to fatigue. Sections 4–6 contain statements regarding how emotions, persons, and situations affect communication. Section 7 concerns the roles in which the patient feels restricted, as a family member, in social and professional situations, etc. In section 8, the patient is encouraged to think about what contributes to their communicative changes, whether it is speech, language, cognition, memory, fatigue or physical difficulties. In section 9, the patient is asked to define how communication is affected, whether they communicate less frequently, with increased difficulty or with the need for assistance from others. Finally, section 10 contains statements that relate to different strategies used to increase communicative function. The patient is instructed to indicate how well each of the 50 statements applies to him or her at the present time by placing an X in one of six boxes labeled 'definitely false', 'mostly false', 'partly false', 'sometimes true', 'mostly true', and 'definitely true'.

In the present study, the scale (definitely false–definitely true) was subsequently transformed to correspond to 0–5 (where 0 indicated definitely false and 5 definitely true regarding statements indicating a communicative problem). All answers were added up to a sum and divided by the number of answered items to give a

Table 1. Subject characteristics (n = 55)

Age, years	55.7 ± 12.4 (27–75)
Sex	
Male	25 (45%)
Female	30 (55%)
Diagnosis	
Multiple sclerosis	26
Parkinson plus syndrome	19
Parkinson's disease	5
Friedreich's ataxia	1
Motor neuron disease	1
Stroke	1
Traumatic brain injury	1
Unclear progressive condition	1
Mean disease duration	163.6 ± 132.7 months (12–480) 13.6 years (1–40)
Mean duration of speech difficulties	58.5 ± 54.3 months (3–276) 4.9 years (0.25–23)
Mean time of education	154 ± 39.6 months (72–228) 12.8 years (6–19)
Degree of professional activity ¹	
Not working	30 (55%)
Working part-time	11 (20%)
Working full-time	7 (13%)
Degree of dysarthria ²	
Mild	30 (55%)
Moderate	16 (29%)
Severe	8 (15%)

¹ Missing data from 7 participants.
² Missing data from 1 participant.

mean of perceived communicative problems caused by the neurogenic speech disorder. Different means for the ten different sections were also calculated.

A translated version of the Communication Profile for Individuals with Dysarthria (the Communication Profile) was used to validate LwD. The Communication Profile is a 100-item self-report questionnaire developed by Yorkston and Bombardier [11] to solicit information in four different areas: *characteristics*, i.e. the patient's perception of the features of the dysarthria, perceived *situational difficulties* (rated according to six dimensions assumed to influence ease of communication: partner familiarity, size of audience, demand for intelligibility, demand for speed, emotional load and environmental adversity), *compensatory strategies* used (classified as improved production, environmental modification, avoidance, message modification or partner instruction) and *perceived reactions of others* (categorized as helpful, solicitous or punishing). The patient is instructed to endorse each statement by indicating 'strongly agree', 'agree', 'neutral', 'disagree', 'strongly disagree' or 'does not apply'. To facilitate comparison with LwD, the scale was transformed to 0–4 (where 0 indicated strongly disagreeing and 4 strongly agreeing to statements indicating a communicative problem) and all items answered 'does not apply' were excluded.

Procedure

Thirty individuals were invited to participate in the study by a speech-language pathologist at the Department of Neurology at Sahlgrenska University Hospital. They were all patients who had been in contact with the department because of their dysarthria during the last 5-year period. Seventeen individuals were participating in an ongoing study of dysarthria in Parkinson plus syndromes and were invited to participate as a part of that study. These 47 individuals received both questionnaires and an information letter by mail and were contacted after a week by telephone, to make sure that they had been able to understand and fill out the questionnaires correctly. An additional 8 individuals were consecutive visitors to the same Department during the time when data from the other two groups were collected. They only answered the first questionnaire, LwD, during the visit or at home whichever they preferred.

The 47 individuals who received both questionnaires answered them at home and could fill out the two questionnaires in any order and take as much time as they needed. Any questions from the respondents were answered at the follow-up telephone call a week after the receipt of the questionnaires and they were then asked to send in the forms. Both questionnaires were answered on paper copies. If a motor disability prevented the participants to use a pen to fill out the form, they were instructed to use a significant other as assistant. As part of the general questions included in part A, the participant was asked the following: This questionnaire was filled out by: () me alone, () me with help from someone else. Four participants had received help to fill out the questionnaires.

Severity of dysarthria was rated on a coarse scale ranging from *none*, *mild*, *moderate* to *severe*. Dysarthria was considered mild when there was a detectable speech disturbance that did not affect intelligibility. Moderate dysarthria was distinguished by a marked reduction in speech intelligibility. Severe dysarthria, finally, was considered when the use of augmentative or alternative communication was needed. These definitions are in accordance with Yorkston et al. [4]. Severity was rated during conversation with the participants, either during their visit or over the telephone by the speech-language pathologist at the Department of Neurology.

Participants

Subject characteristics are presented in table 1. The participants were 25 men and 30 women with a mean age of 55.7 years with a standard deviation of 12.4 and a range of 27–75 years. Diagnoses were almost exclusively progressive neurological disorders: 26 individuals had multiple sclerosis, 19 had a Parkinson plus syndrome, and 5 had Parkinson's disease. Mean disease duration was 13.6 years with a range of 1–40 years. Mean duration of speech difficulties was 4.9 years with a range of 3 months to 23 years. Mean number of years in education was 12.8 years with a range of 6–19 years. Seven individuals were working full-time, 11 part-time and 30 were not working (due to retirement or sick-leave). Eight individuals were considered to have severe dysarthria, while 16 had moderate and 30 mild dysarthria. Reports on degree of professional activity were missing for 7 individuals and degree of dysarthria for 1 individual.

The individuals were not selected in order to comprise a homogeneous group. As a broad selection of diagnoses, dysarthria types and severity was desirable, the group consisted of all the patients that were in contact with the clinic at the time of study.

Statistical Methods

Results were analyzed first of all in terms of percentage individuals indicating 'mostly true' or 'definitely true' (4 or 5) regarding all statements included in LwD. In addition, means, ranges and standard deviations for the ten sections and the entire questionnaire were calculated. In order to explore relationships with background factors such as age, gender, diagnosis, disease duration, duration and degree of dysarthria, education and employment status, nonparametric statistics were used (Spearman's rank correlation coefficient, Mann-Whitney U test, Kruskal-Wallis one-way ANOVA test). Finally, Spearman's rank correlation coefficient was used to assess degree of association between subscores on LwD and the Communication Profile.

Results

Table 2 presents all statements included in the questionnaire LwD and the percentage of individuals who indicated 'mostly true' or 'definitely true' (4–5). Nine statements were endorsed by more than 45% of the individuals. They were (in descending order of magnitude): 'The speech difficulties themselves (rather than language, cognition and/or physical difficulties) contribute to the communication problems' (61.9%), 'My speech difficulties negatively affect my self-image' (52.7%), 'My difficulties in communicating affect my possibilities to actively take part in work and studies in the way I would want to' (52.7%), 'It's difficult to talk in a group of people that I don't know' (50.9%), 'My speech difficulties get worse when I'm angry or sad' (49.1%), 'I often need to repeat what I've said because people don't understand me' (47.3%), 'My difficulties in communicating affect my possibilities to express my personality in the way I would want to' (47.3%), 'I make only short remarks in discussions or conversations' (45.5%), 'My speech is slow' (45.4%). Eight statements were endorsed by 40–45% of the individuals. They were: 'I don't communicate in the way that I would want to' (43.7%), 'I communicate like I want to, but not as much or as often as I would like' (43.7%), 'Fatigue contributes to the communication problems' (43.6%), 'I don't speak if I think that it'll be hard to make myself understood' (43.6%), 'I worry about my speech difficulties' (43.4%), 'I avoid situations where I'm expected to talk (41.8%), 'I avoid "deep" or complicated discussions or conversations' (40.0%) and 'I communicate like I want to, but it's difficult' (40.0%).

Group means, ranges and standard deviations for the ten different sections and the entire questionnaire are presented in table 3. The possible range was 0–5, and a higher mean indicates more severe communication problems. In this group of individuals with dysarthria, com-

munication problems related primarily to speech were more commonly endorsed than language/cognition- and fatigue-related problems. Emotions were reported to have effects on communication more often than different situations and persons. Variability was generally high, as indicated by the large standard deviations.

Association with Other Background Factors

No significant correlations were found between mean scores and section scores on LwD, and age or disease duration. No significant differences were found between men and women or between degrees of professional activity. Possible differences between diagnoses were explored using Kruskal-Wallis one-way ANOVA comparing the larger three groups (multiple sclerosis, Parkinson plus syndrome and Parkinson's disease) and were found to be nonsignificant. There was a moderate but significant positive correlation between mean score on LwD and reported duration of dysarthria ($r_s = 0.297$, $p \leq 0.05$), and a negative correlation with number of years in education ($r_s = -0.366$, $p \leq 0.01$). Mean scores on LwD for the three subgroups mild ($n = 30$), moderate ($n = 16$), and severe ($n = 8$) dysarthria are shown in figure 1. The group with moderate dysarthria has a higher score, indicating more communication problems, but the differences between the groups are not significant (Kruskal-Wallis one-way ANOVA test, $p = 0.12$).

Association with Scores on the Communication Profile

Although the scales were different (LwD had a range of 0–5 and the Communication Profile 0–4), the correlation was relatively high ($r_s = 0.683$, $p \leq 0.01$). In addition, five different statements from three different sections were selected, matched and correlated with corresponding statements from the Communication Profile (all from the section comprising statements on situational difficulties). Results are presented in table 4. Correlations are generally moderate to high (0.4–0.7) and significant.

Discussion

In summary, the results of this questionnaire study including 55 individuals with acquired dysarthria indicated that both degree and type of subjectively perceived communicative difficulties were varying. Degree of communicative difficulties was not related to age, gender, diagnosis, disease duration or degree of professional activity in this group.

Table 2. Percentage of individuals indicating mostly true or definitely true (4–5) regarding all statements (n = 55)

Section	Statement	%
1 Communication problems related primarily to speech	I often run out of air when I talk	30.9
	I often sound hoarse	29.1
	My speech is slow	45.4
	My speech is slurred	32.8
	I often need to repeat what I've said because people don't understand me	47.3
2 Communication problems related primarily to language/cognition	I have difficulty finding words when I speak	6.4
	My speech is not very complex (e.g. short sentences, simple grammar)	29.1
	I need to think about what I'm saying and how I'm saying it when I speak	29.1
	Understanding new information takes a long time	12.7
	I don't always understand what people say to me	5.4
3 Communication problems related primarily to fatigue	I rarely start a conversation	16.3
	I avoid 'deep' or complicated discussions or conversations	40.0
	I avoid situations where I'm expected to talk	41.8
	I make only short remarks in discussions or conversations	45.5
	I cannot manage to concentrate enough to follow what is being said	18.2
4 Effects of emotions	My manner of communicating varies in a way that's difficult for me to predict	32.7
	My speech difficulties get worse when I'm angry or sad	49.1
	My speech difficulties negatively affect my self-image	52.7
	My mood affects how I interact with others and how I communicate	27.2
	I worry about my speech difficulties	43.4
5 Effects of different persons	I'm treated differently by people that I communicate with	18.2
	It's difficult to communicate with members of my family	7.3
	It's difficult to communicate with relatives and friends	14.5
	It's difficult to communicate with people I know, at work or in stores	16.4
	It's difficult to communicate with people that I've never met before	36.3
6 Effects of different situations	It's difficult to talk with one or two people at home	14.6
	It's difficult to talk when we have friends visiting	20.0
	It's difficult to talk on the telephone	38.2
	It's difficult to talk in a group of people that I don't know	50.9
	It's difficult to talk about emotional things	23.7
7 My difficulties in communicating affect my possibilities to ...	express basic need (get attention, express feelings, etc.)	25.4
	express basic need (get attention, express feelings, etc.)	25.4
	exercise my role as a family member in the way I would want to	34.5
	take part in social gatherings with relatives and friends in the way I would want to	34.5
	actively take part in work and studies in the way I would want to	52.7
8 What do you think contributes to the changes in the way you communicate?	express my personality in the way I would want to	47.3
	The speech difficulties themselves	61.9
	Difficulties with the language	9.1
	Difficulties in thinking, remembering and concentrating	20.0
	Fatigue	43.6
9 Communicating like I would want to:	Physical difficulties	34.5
	I don't communicate in the way I would want to	43.7
	I communicate like I want to, but not as much or as often as I would like	43.7
	I communicate like I want to, but it's difficult	40.0
	I communicate like I want to, but listeners often fill in words or try to help out	25.5
10 How do you perceive changes and the possibility to alter your way of speaking?	I have to rely on others to be able to communicate like I want to	20.0
	I believe that my speech can be changed	36.3
	I explain my communication difficulties to other people	32.7
	I try to express myself in another way when I'm not understood	27.2
	I take a break and rest a little when I notice that I'm not being understood	27.3
	I don't speak if I think that it'll be hard to make myself understood	43.6

Table 3. Means, ranges and SDs for the ten sections of and the entire questionnaire LwD

Section	Mean	Range	SD
1 Communication problems related primarily to speech	2.7	0.2–4.8	1.0
2 Communication problems related primarily to language/cognition	1.8	0–4.6	1.1
3 Communication problems related primarily to fatigue	2.3	0–5	1.5
4 Effects of emotions	2.9	0–5	1.2
5 Effects of different persons	2.0	0–4.4	1.3
6 Effects of different situations	2.4	0–5	1.3
7 Role restriction	2.8	0–5	1.4
8 Causing factors	2.5	0.6–5	1.0
9 Type of restriction	2.7	0–4.8	1.1
10 Strategies	2.5	0–4.6	1.2
All sections/the entire questionnaire	2.4	0.6–4.4	0.9

Possible range 0–5 (0 = definitely false, 1 = mostly false, 2 = partly false, 3 = sometimes true, 4 = mostly true, 5 = definitely true), higher mean indicated more pronounced problems (n = 55).

Table 4. Correlations (Spearman's rank correlation) between six pairs of statements from each of the two questionnaires LwD and Communication Profile (ComPro)

Section	Statement LwD	Statement ComPro	Correlation
Effects of emotions	My speech difficulties get worse when I'm angry or sad	It's difficult for me when I am upset and try to get a point across	$r_s = 0.473$ $p \leq 0.001$
	It's difficult to talk about emotional things	It's difficult for me when I am talking with a close friend about emotional issues	$r_s = 0.693$ $p \leq 0.001$
Effects of different persons	It's difficult to communicate with members of my family	It's difficult for me when I am talking with my family after dinner	$r_s = 0.584$ $p \leq 0.001$
	It's difficult to communicate with relatives and friends	It's difficult for me when I am talking with a friend or family member in a quiet room	$r_s = 0.590$ $p \leq 0.001$
Effects of different situations	It's difficult to talk on the telephone	It's difficult for me when I am in a quiet room at home talking on the telephone	$r_s = 0.555$ $p \leq 0.001$

Generally, the overriding problems (defined as the statements endorsed by the largest number of participants) were related to a negative self-image and restrictions in communicative participation, i.e. possibilities to actively take part in work and studies and to express their personality were affected. Communication was also affected by emotions and by the number and familiarity of people present in communicative encounters. The dominating speech difficulties were related to decreased speech rate and a need for repetition as a consequence of misun-

derstandings. This is in accordance with Yorkston et al. [12], where 50–80% of items related to situational difficulties were endorsed by the individuals with dysarthria. Emotional load and demand for intelligibility and speed, as well as general environmental adversity, were the situational dimensions more frequently reported as difficult. Size of the audience and partner familiarity was somewhat less influential, but the difference was not significant. Similar results were described by Hartelius et al. [15], where the most frequently perceived situational dif-

Fig. 1. Mean scores on LwD for the three subgroups mild ($n = 30$), moderate ($n = 16$), and severe ($n = 8$) dysarthria. Differences are not significant (Kruskal-Wallis one-way ANOVA, $p = 0.12$).

ficulty was related to the size of the audience. Antonius et al. [13] reported means between 53 and 58% of items related to situational difficulties endorsed by dysarthric participants. Statements relating to sense of effort in communicating, fatigue, avoidance and worry were also frequently endorsed. Similar findings were reported by a group of individuals with multiple sclerosis [16].

Slow rate is a distinctive feature of several types of dysarthria, including spastic, ataxic, hyperkinetic and the mixed dysarthrias associated with multiple sclerosis, ALS and the Parkinson plus syndromes [3]. It is also an early symptom, frequently used as a compensatory mechanism. It is therefore not surprising that slowness of speech was the most frequently reported speech-related communication problem.

The fact that age, gender, diagnosis, or disease duration had no significant impact on perceived communicative difficulties highlights the fact that these difficulties are indeed subjective and cannot be predicted on the basis of simple background factors. Furthermore, the fact that progression of speech deterioration in different degenerative diseases varies considerably might contribute to the lack of correlation between disease duration and degree of perceived communicative difficulties. For example, in Parkinson plus syndromes a speech disturbance can be one of the first signs, while individuals with Parkinson's disease usually develop speech symptoms late in the disease process.

Severity of dysarthria had no statistically significant effect on perceived communicative difficulties. However,

the LwD mean of the group with moderate dysarthria was slightly higher than in the severe and the mild groups, although the difference was not statistically significant. Several authors have stressed the importance of exploring the relationship between severity of dysarthria and perceived communicative difficulties, or in ICF terminology, the relationship of functional impairment to activity limitation and participation restriction, including Hustad et al. [17] and Yorkston et al. [12]. The anticipated finding would be that the individuals with severe dysarthria perceive their difficulties as greater than the individuals with moderate and mild dysarthria. However, Hustad et al. [17] emphasize that the relationship between the different levels (dysarthric impairment vs. communicative activity limitation and participation restriction) is not likely to be linear and that it is important to assess each level separately. Severity of dysarthria does not necessarily predict extent of communicative participation. Yorkston et al. [12] investigated whether speakers with mild, moderate, and severe dysarthria differed in perceived speech characteristics, situational difficulties, compensatory strategies and reactions of others. They found a significant difference between severity groups only in perceived reactions of others, in that individuals with severe dysarthria felt that partners were more influential in communication exchanges than individuals with mild or moderate dysarthria. The authors were somewhat surprised by the lack of differences among the severity groups, concerning other aspects (number of speech characteristics endorsed, type and frequency of situations felt to be difficult, and the number of compensatory strategies found to be beneficial). The authors concluded that asking questions about perceived reactions of others might be a reasonable means of assessing the degree of handicap associated with dysarthria. In the present study, although not statistically significant, the group with moderate dysarthria reported more communicative difficulties than the other two severity groups. A cautious interpretation of this finding is that an individual with moderate dysarthria might be maintaining a professional and social life that is more communicatively demanding than a person with severe dysarthria is. Severity of speech disorder in neurological disease also frequently mirrors severity of disease symptoms in general, and an individual more seriously affected by a progressive disease might have other more pronounced symptoms to handle, as well as a more restricted lifestyle. In conclusion, there seems to be no unequivocal relationship between severity of dysarthria and perceived communicative difficulties, and the issue calls for further exploration.

The negative correlation between degree of perceived communicative problems and number of years in education would seem to indicate that fewer years in education imply more communicative problems in individuals with dysarthria. However, the correlation was moderate and the number of participants relatively small, thus no conclusions should be drawn. It has, in fact, been shown that physical functioning and perceived health increase significantly with years of formal education [18].

It is important that assessment protocols including subjectively perceived communication problems should not be too extensive and time-consuming. One of the aims of the present study was to establish whether the information gained from the present questionnaire was comparable to information from the more extensive Communication Profile. Judging from correlations between the two different protocols in their entirety, as well as between individual statements, the correspondence was relatively good. It seems that a shorter protocol might be able to capture the same type of perceived difficulties.

The fact that communicative difficulties are perceived very differently indicates the need for individualized treatment planning. Subjective difficulties are not neces-

sarily reflections of severity of speech symptoms, and systematic protocols are needed to help identify problems that need addressing in intervention. Systematic subjective reports should always be included in the assessment of individuals with acquired dysarthria.

The present study suffers from a number of limitations that call for wariness in interpretation of results. The classification of severity of dysarthria was crude and only done by one clinician. Although the selection of questionnaire items was based on published scales and interview data and appeared to have good ecological validity, a few statements turned out to be problematic in the sense that they were cognitively demanding or could be related to several different factors. Statistical handling was limited and inpatient reliability data were not gathered. However, as a result of the present study, the questionnaire has been revised and is presently being used in an investigation of self-perceived communicative difficulties in relation to dysarthria test scores and intelligibility in a larger group of individuals. These individuals will be followed longitudinally to see how degree of dysarthria, intelligibility and self-perceived difficulties related to communicative function, activity and participation develop over time in degenerative neurological conditions.

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