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# Sense of coherence is a sensitive measure for changes in subjects with Parkinson's disease during 1 year

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## Sense of coherence is a sensitive measure for changes in subjects with Parkinson's disease during 1 year

To investigate subjective and objective changes in function in subjects with Parkinson's disease (PD) home visits with interviews were performed with a 1-year interval. Depressive symptoms were rated with the Geriatric Depression Scale, subjective health with the generic SF-36 scale and the disease-specific PDQ-8 scale; objective changes were assessed according to the Hoehn and Yahr scale; insomnia was rated with an eight-item questionnaire and the sense of coherence (SOC) was determined with the short version of that scale. A total of 91 subjects (39 women and 52 men with a mean age of 70 years) living at home, most of them moderately to severely disabled, were interviewed. Time since diagnosis was

<2 years for 13%, 2–10 years for 55%, and >10 years for 32%. During the studied year the subjects' status declined significantly as shown by changes in both the PDQ-8 and the Hoehn and Yahr scales. The most striking finding was a pronounced decrease in the SOC scale ( $p < 0.0001$ ). This indicates that the subjects' ability to handle stress-related problems secondary to the progress of disease might have decreased. In order to optimize nursing care for subjects with PD, in addition to medical treatment, an assessment of the SOC could aid nursing staff in evaluating subjects' ability to handle their life situation.

**Keywords:** Parkinson's disease, sense of coherence, salutogenetic model, nursing care, PDQ-8, SF-36, Geriatric Depression Scale, Hoehn and Yahr.

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## Introduction

Parkinson's disease (PD) is the second most prevalent neurodegenerative disorder after Alzheimer's disease. In Sweden, the incidence is 11–12 per 100 000 person-years and the prevalence is 115–125 per 100 000 person-years (1). This means that roughly 15 000–20 000 subjects in Sweden live with PD, and that every year about 1000 Swedes are diagnosed with the disease.

In addition to motor disturbances, subjects with PD also experience emotional, cognitive, sensorial and autonomic disorders that entail functional and psychosocial impairment (2). All these symptoms have a negative effect on the subjects' health-related quality of life (HQoL), and cause them to experience uncertainty in activities of daily life, suffer from restrictions in social and professional opportunities, and live with the threat of falls and injuries (3).

This study is a part of a larger investigation about HQoL in subjects suffering from PD. The study started in 1998 and was focused on both somatic symptoms and signs as well as on emotional symptoms; that is on subjective and objective health status and on depressive symptoms, insomnia and ability of coping. Subjective and objective health were greatly impaired, depressive symptoms and insomnia were common, female patients were stigmatized by their disease and the patients' relatives experienced a great caregiver burden (4–6). As PD is progressive, it was considered of great interest to study changes 1 year after the first investigation, and therefore a follow-up was conducted. In both investigations the same variables were studied.

In studies of cancer patients and stroke victims the coping capacity has shown relationships to treatment results and to the risk of burnout (7–9). Therefore, an assessment of the coping capacity in the patients could help increase the understanding among the nursing staff of the subjects' ability to handle their life situation (10, 11).

The aim was to investigate subjective and objective changes during 1 year in subjects with PD. More specifically the following variables were studied: subjective and objective health, depressive symptoms, insomnia and coping ability. As PD is progressive and multisymptomatic,

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it was considered of interest to show which of the variables that changed most during 1 year.

## Material and methods

### Subjects

Every third subject registered between 1 January 1997 and 31 December 1997 at the outpatient PD clinic of the neurology department at the Lund University Hospital was invited to take part. One hundred twenty-four possible subjects were recruited. Twenty subjects subsequently refused to participate, primarily because they considered themselves too tired or too sick to participate. These 20 individuals did not differ from the participants regarding age, gender or duration of illness. Upon further investigation it was found that two of the subjects did not have PD and were excluded. Thus, 102 subjects remained (participation rate 80%): 43 women with a mean age of 70 years (range 58–79) and 59 men with a mean age of 71 years (range 56–79). Three diagnose groups were created according to the length of the disease. Fourteen per cent had had their diagnosis for <2 years, 57% for 2–10 years, and 31% for more than 10 years. Twenty-nine subjects (11 women and 18 men) were diagnosed before the age of 60. Ninety per cent of the subjects were co-habiting with a spouse, child or male/female friend and 10% lived alone. Ninety-eight per cent of the subjects were being treated with L-dopa and 20% were also taking additional drugs for PD.

One year after the first investigation, a follow-up was performed. Ninety-one subjects were still alive of the original 102, and constituted the population for this study. Characteristics of these subjects are presented in Table 1.

### Assessments

*Sense of coherence.* The Sense of Coherence (SOC) scale captures global subjective states of coping with everyday life in relation to holistic notions of health and well-being (11, 12). Coping is the way an individual reacts to problems and conflicts, such as having to live with a progressive degenerative disease such as PD. In this study the short version of the SOC was used which comprises 13 statements. The SOC covers three main areas of importance to coping: comprehensibility (five items), manageability (four items) and meaningfulness (four items) (11, 12). According to Antonovsky the scale should be used as a whole and the three components should not be presented as subscales (11, 12). The scale has a seven-point response format, with a greater number of points representing a stronger SOC. The scores range from 13 to 91. The stronger the SOC, the more likely it is that the person will be able to cope successfully with stressful situations. The scale has a high validity and homogeneity (12).

**Table 1** Characteristics of the subjects at the first investigation (n = 91)

Variable	
Mean age (years)	
Women	70 ± 5 (range 59–80)
Men	70 ± 6 (range 57–80)
Gender	
Women	39
Men	52
Marital status	
Married	65
Unmarried	2
Co-habiting	3
Divorced	8
Widow/widower	12
Type of dwelling	
Own house	41
Own flat	14
Rented flat	36
Education	
Primary school	38
High school	28
University	25
Duration of illness	Mean 10 years (range 2–35)
Diagnose groups	
<2 years	13%
2–10 years	55%
>10 years	32%
SOC (median)	
<2 years	79
2–10 years	73
>10 years	73
Depressive symptoms	
Without depressive symptoms	75%
Mildly depressed	25%
Hoehn and Yahr	
Group 1	18 patients
Group 2	19 patients
Group 3	20 patients
Group 4	17 patients
Group 5	17 patients
Insomnia	80%

*The SF-36 scale.* This comprises a total of 35 items that make up eight scales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health. These eight areas are assumed to be universal and to represent basic human function and well-being (13–15). Moreover there is one item about changes in health over the past year (13). Subject scores in each domain are linearly transformed to a 0–100 scale, with 100 indicating the most favourable health state. The SF-36 can provide information on the impact of a disease on physical and mental health as related to published norms. The Swedish version of the SF-36 has been translated and validated against a norm group by

Sullivan and colleagues (13). Thorough standardization is provided regarding content, how the scores are calculated and the framework of the health profile (13–15).

*Depressive symptoms (GDS).* Depressive symptoms were rated with the 15-item version of the Geriatric Depression Scale (GDS). The scale has been shown to have satisfactory validity (16), and positive answers to 0–5 items are considered as normal, positive answers to 6–10 items as mildly depressed state, and positive answers to 11–15 items as very depressed state (16). In this study the scale was used as an ordinal scale with more positive answers indicating a more depressive state (Table 1).

*Functional status (Hoehn and Yahr scale).* Subjects were classified into five groups characterized by successively greater disability, according to the Hoehn and Yahr scale (17). Subjects in group 1 have minimal or no functional impairment, those in group 2 have bilateral or midline involvement but with no impairment of balance, those in group 3 have significant tremor, rigidity and/or bradykinesia and mobility problems, those in group 4 have more pronounced disability but are still mobile and able to function independently, and those in group 5 are confined to a bed or wheelchair unless they receive assistance (Table 1).

*Subjective health (PDQ-8).* For this purpose the PDQ-8 scale, a disease-specific instrument, was used (18, 19). It covers eight dimensions of health that subjects with PD report as being adversely affected by the disease: mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication and bodily discomfort. All items are scored on a scale from 0–100, and lower scores indicate better-perceived health status. The results can be presented either in profile form or as a single index, as in this study. The scale has a satisfactory validity and homogeneity (18, 19).

*Insomnia.* Insomnia was diagnosed using the questionnaire by Livingston. It contains eight yes/no questions: difficulty falling asleep, taking or being dependent on medication to help one sleep, sleep interrupted during the night, difficulty sleeping owing to moods or tension, difficulty sleeping owing to pain or itching, inability to return to sleep after waking at night, waking early, feeling tired and sleeping more than 2 hours during the day. Two or more yes answers indicate caseness, which is a clinically significant insomnia (Table 1). The scale has a satisfactory validity and homogeneity (20).

The homogeneity of the scales from the first investigation was 0.80 for GDS, 0.74 for PDQ-8, 0.93 for SF-36, 0.79 for SOC and 0.54 for the Insomnia scale.

An experienced PD nurse (MCA) administered all interviews with the subjects in their homes. The interviews lasted 40–60 minutes.

## Statistics

All scales were ordinal scales and nonparametric tests were therefore used. Comparisons between the first and second investigation were made with the Wilcoxon test. Kruskal–Wallis test was used for comparisons between the three diagnose groups. Correlations between the six scales were performed according to Spearman. The homogeneity of the scales was calculated according to Cronbach's alpha. Two-sided tests were used and a p-value of <0.05 was considered statistically significant.

## Ethics

The Ethics Committee of the University of Lund, Sweden, approved the study (LU 255-97).

## Results

The subjects' functional status, as assessed with the Hoehn and Yahr scale, deteriorated significantly between the first and second investigation ( $p < 0.01$ ). The subjective assessment of health with the disease-specific scale, the PDQ-8, also deteriorated significantly between the first and second investigation ( $p < 0.01$ ), as did the SOC scale from a median of 74 at the first investigation to 47 at the second ( $p < 0.0001$ ). There was no significant difference in SOC between the three diagnose groups at the first investigation ( $p = 0.15$ ), neither at the second investigation ( $p = 0.08$ ), and the decline in SOC between the first and second investigation was of the same magnitude in the three diagnose groups. The GDS, the Insomnia scale and the SF-36 did not change significantly (see Table 2).

Correlations between the six variables studied are presented in Table 3.

## Discussion and conclusions

This study showed marked differences in the subjects with PD during 1 year, both objective changes as measured with

**Table 2** Changes during 1 year for the subjective assessments SOC, PDQ-8, GDS, the Insomnia scale, SF-36, and the objective assessment Hoehn and Yahr ( $n = 91$ )

Variable	Year 1	Year 2	<i>p</i>
SOC	74 (75)	47 (46)	0.0001
Hoehn and Yahr	3 (2.71)	3 (2.96)	0.01
PDQ-8	10 (10.4)	8 (8.9)	0.01
GDS	5 (5.2)	4 (5.1)	ns
Insomnia	3 (3.1)	3 (3.2)	ns
SF-36	48 (47.6)	48 (48.4)	ns

SOC, sense of coherence; GDS, Geriatric Depression Scale; ns, not significant.

Medians (and mean values within parenthesis).

**Table 3** Correlations (Spearman) between the six variables

Variables	Hoehn and Yahr				
	PDQ-8	GDS	Insomnia	SF-36	
SOC	0.32**	0.53***	0.55***	0.29**	0.56***
Hoehn and Yahr		0.52***	0.34**	0.20 ns	0.53***
PDQ-8			0.66***	0.42***	0.72***
GDS				0.32**	0.74***
Insomnia					0.47***

SOC, sense of coherence; GDS, Geriatric Depression Scale.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ . Data from the first investigation.

the Hoehn and Yahr scale, and subjective changes as measured with the PDQ-8 scale, which indicated a parallel deterioration in function. These disease-specific scales are sensitive to changes in function and a deterioration during 1 year is therefore not surprising. However, the most striking feature was the pronounced change in the SOC scale whereas neither the Insomnia scale, nor the GDS scale or the SF-36 scale showed any changes. These three scales are not disease-specific, although depression and insomnia are common in PD (4), which might explain why they did not change.

The SOC scale captures global subjective states of coping with everyday life in relation to holistic notions of health and well-being (11, 12). According to Antonovsky's hypothesis, a person having entered patienthood has entered a stressor situation and the stronger the SOC world outlook of a person, the more likely he or she will be able to cope successfully with the stressor situation (21). The SOC does not refer to a specific type of coping strategy, but to factors that, in all cultures, always are the basis for successful coping with stressors (12). In his salutogenetic model Antonovsky described health as a continuum between ease and disease rather than a health-disease dichotomy. An individual's SOC is a crucial determinant of one's position on the health continuum (11).

Antonovsky's assumption is that SOC shows a stable and long-lasting way of looking at the world. However, temporary changes in the SOC might occur, equivalent to fluctuations around a personal mean to which the individual will soon return. A disease, for example, can produce a temporary effect (22). However, a recent study of a general population sample has shown that SOC declined during a 5-year period, and this decline was more pronounced in the elderly and in those who had an identified disease (22). This is in agreement with the results from the present study where SOC median score decreased significantly between the first and the second year ( $p = 0.0001$ ). It is not known whether this is a temporary decrease or a permanent one, as we have just two measurements. This decrease in SOC might indicate that the subjects' ability to handle the problems secondary to the progression of the disease had decreased. SOC values did not differ between

the three groups with different time since diagnosis, neither in the first nor in the second investigation, and the decrease in SOC was of the same magnitude irrespective of time since diagnosis. Associations between high and low SOC and variables relate to patient structure and social context (22–24). The concept of SOC introduces a new dimension to health but further studies are needed to sort out what the SOC really is measuring. In one study SOC showed a high correlation with anxiety and depression (22). In the present study SOC also had a high correlation with the GDS as well as with the PDQ-8 and the SF-36 (Table 3). In general, the SF-36 showed the highest correlation with the other scales, which might be explained by its wide range of symptoms, covering aspects found in all the other scales. However, it did not change significantly during 1 year. The coping capacity should be of clinical importance to identify those in need of increased and prolonged support as has been shown in a study of patients with a malignant disease (9). In a study of cancer subjects, Persson et al. (7) found that subjects who did not relapse had higher SOC scores at the beginning of the treatment than subjects who relapsed. Their assumption was that the subjects who relapsed may have had different prerequisites or had been in a worse position at the onset of the disease (7). The subjects in the present study, with the progress of their disease, were in a similar position as were the relapsed patients in the study by Persson et al. (7). Nilsson et al. (8) studied stroke victims and spouses and found that individuals with a weak SOC clearly displayed more difficulties in coping with situation and risk of burnout, than did those with a strong SOC.

Individuals with a moderate SOC tend to move to a lower level over time, as the encounters with stressors entail exhaustion of strength, and it is not possible to balance the stressors adequately by individual resources during a lifetime (22). This observation may be even more valid concerning individuals with a weak SOC, where the stressors play an increasingly conspicuous role and where life may become chaotic, unmanageable and meaningless (11, 21). The subjects in the present study had moderate SOC scores at the first investigation, and thus two reasons could be attributed for the decrease in SOC: a tendency to move to a lower level over time, irrespective of disease, and progression of the disease.

The PDQ-8 scale used in this study was developed out of the PDQ-39 scale and contains the most highly intercorrelated items from each dimension of the original 39 items and has been recommended for use where a short measure, which can provide an overall score, is sufficient (18). The short form, the 13-item, version of the SOC scale used here was developed from the original 29-item scale and is more convenient for clinical use and has a satisfactory validity (18). The homogeneity of the scales was quite satisfactory, and comparable with findings by other authors (12, 13, 16, 18). The Insomnia scale had a homogeneity of 0.54, similar to 0.56 found in another study (20).

The patients in the present investigation were all treated at a specialist clinic and were therefore probably optimally treated. About a quarter of the subjects had a university education and all patients lived at home and none lived in nursing homes or facilities for the elderly. Moreover, no patient showed obvious cognitive dysfunction and all took part in the interviews. The material might therefore represent a more healthy part of the Parkinson population. However, the patients' mean Hoehn and Yahr score and a mean duration of disease were comparable with PD patients in another study where such data were reported (25). All patients had been familiar with the study, as well as with the nurse who conducted all the interviews, for over a year. The quality of the data is good. If the patient did not understand a certain question, the interviewer explained the question briefly in a friendly and neutral manner. As far as we know no other studies have used the SOC scale in subjects with PD. In that respect this study is unique.

This study investigated functional changes in subjects with PD during 1 year and has shown the SOC to be very sensitive to change. Subjective and objective measures such as the PDQ-8 and the Hoehn and Yahr scales confirmed the progression of the disease. This decrease in SOC might be of importance for the subjects' ability to handle stress-related problems secondary to the progression of chronic disease (22). In order to optimize nursing care for subjects with PD, in addition to medical treatment, an assessment of the SOC could aid nursing staff in evaluating subjects' ability to handle their life situation (10, 26).

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### Author contribution

Both authors designed the study and both drafted the manuscript, with Marianne Caap-Ahlgren having greater involvement. Marianne Caap-Ahlgren was responsible for the computer work and Ove Dehlin gave advice on statistical calculations.

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### Ethical approval

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