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A ONE YEAR STUDY OF COPING, SOCIAL SUPPORT AND QUALITY OF LIFE IN PARKINSON'S DISEASE

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The role of coping and social support in the quality of life for Parkinson's Disease (PD) patients is not well understood. Most studies are cross-sectional and concentrate on depression as an outcome measure. The aim of the present study was to explore the role of coping and social support in quality of life for patients with PD. Self-report measures were completed by 105 sufferers of PD; 75 completed the same questionnaire a year later. Patients had the most problems with social function, followed by problems with mobility control and psychological autonomy and communication. After controlling for age, gender and illness duration, the number of PD symptoms predicted mobility control, social functioning and psychological function. Passive coping explained additional variance in most functional domains with more passive coping being related to increased problems. The quality of life was highly stable over the course of the year. Active coping was related to superior psychological functioning one year later. In fact, this was the only coping and social support variable related to functioning after one year, when controlling for previous functions. The results are discussed in terms of the importance of symptom management in PD.

KEY WORDS: Parkinson's disease, quality of life, coping, social support, longitudinal, sickness impact profile.

Parkinson's Disease (PD) is a chronic degenerative neurological ailment. Tremor, muscular rigidity, bradykinesia, postural instability and a loss of facial expression are the most characteristic physical symptoms (Pearce and Jones, 1994). Patients may also suffer from such cognitive deficits as concentration and memory problems while anxiety and feelings of depression are common in sufferers of Parkinson's Disease (Dakof and Mendelsohn, 1986; Gotham, Brown and Marsden, 1986; Ring, 1993).

Depression is frequently studied in PD patients. In general, depression in PD is approached from a biomedical view, seen as a concomitant symptom of the disease and considered a consequence of neurological impairment. However, the symptoms of PD are known to relate only moderately to depression while psychosocial aspects of PD appear to play a role (for overviews, see Brown and Jahanski, 1995; Dakof and Mendelsohn, 1986; Gotham *et al.*, 1986). PD has a profound impact on a patient's daily life. This impact is recognised in the literature, but the number of studies addressing the quality of life in PD patients is limited. Furthermore, in the light of the extensive literature on adaptation processes to chronic disease (see Maes, Leventhal and De Ridder, 1996), the paucity of studies on coping and social support in PD is striking. A literature search of the Medline and Psychlit research indexes produced only a few cross-sectional studies, the results of which are summarised in Table 1.

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Table 1 Studies of coping and social support in Parkinson's Disease

Study	*Sample N (males) Age (range)*	*Measures Coping/Social support*	*Results*
Brod, Mendelsohn, Roberts, 1998	101 (60) 72 (60–86)	based on interviews: coping: avoidance of negative thoughts social support: satisfaction, social isolation	–more avoidant coping related to more severe motoric, psychological, cognitive problems –more social support associated with less severe motoric, psychological problems –more social isolation related to more severe psychological, cognitive problems
Dakof and Mendelsohn, 1989	44 (24) 65 (50–80)	interview; 4 clusters: 1. sanguine, engaged coping 2. depressed, worried, 3. depressed, misunderstood 4. passive, resigned	–depression highest in cluster 3, lowest in 1 –motor functioning lowest in 3, highest in 1 –cognitive functioning lowest in 4 –no associations of clusters with demographics, disease duration or other chronic conditions
Ehman, Beninger, Gawel, Riopolle, 1990	45 Parkinson (PD) (22) 67 (51–85) 24 disabled controls (CO) (10) 65 (52–78)	Moos Coping Questionnaire (Billings and Moos, 1981) Louisville Social Support Scale (Murell *et al.*, 1981)	–PD: more active-cognitive and active-behavioural coping than avoidance coping –PD more active-cognitive and active-behavioural coping than CO, no differences in social support PD: more active-cognitive coping associated with lower depression, less disability, more social support; more active-behavioural coping with lower age; more avoidance coping with more medical problems; social support not correlated with depression
Fleminger, 1991	30	Social Stress and Support Interview (Jenkins *et al.*, 1981)	–social stress and support is a better predictor of anxiety and depression than disease severity
Hermann, Freyholdt, Fuchs, Wallesch, 1997	54 PD (33) 64 (47–75) 50 stroke (34) 62 (24–79)	Freiburg Questionnaire on Coping with Illness (Muthny, 1989)	–active coping and distraction predominate as coping strategies –more active coping and religious relief/quest for sense with PD than with stroke –no relations of coping to depression, motor impairment or psychosocial changes
MacCarthy and Brown, 1989	136 (75) 65 (SD 9.5)	Ways of Coping Checklist (Folkman and Lazarus, 1985) Significant Other Scale (SOS) (Power *et al.*, 1989)	–depression predicted by functional disability, self-esteem, coping by acting out and distraction –positive affect predicted by self-esteem, coping by problem solving, reorientation and distancing, instrumental support
Speer, 1993	26 PD (23) 70	Interpersonal Evaluation List (Cohen, Mermelstein, Kamack and Hoberman, 1989)	–more perceived emotion support related to less depression and physical complaints –more social activities related to less depression, less stress

Studies of coping with the stress of chronic disease generally show that active coping, whether it is directed at a problem situation or emotions, is more fruitful than passive avoidance (De Ridder and Schreurs, 1996; Maes *et al.*, 1996). This also seems also to be the case for PD although the results are not unequivocal. Active problem-oriented and emotion-oriented coping are generally associated with positive mood and decreased feelings of depression while avoidance is generally associated with increased feelings of depression and more severe problems with motor, psychological and cognitive function (Brod *et al.*, 1998; Ehman *et al.*, 1990; MacCarthy and Brown, 1989). In one study, however, coping was not found to be related to depression, motor functioning or psychological functioning (Hermann *et al.*, 1997). Given the cross-sectional nature of these studies, however, the direction of the observed effects is also not clear. Is active coping adaptive and is avoidance maladaptive in case of PD or do increased depression and a lesser quality of life prompt more avoidance and impair active coping skills? Coping skills may certainly be limited by the particular characteristics of the disease. For instance, PD patients are known to be less effective in active-cognitive coping than disabled controls (Ehman *et al.*, 1990). In fact, their use of coping strategies resembles that of stroke patients (Hermann *et al.*, 1997). In a study by Dakof and Mendelsohn (1989), moreover, those patients who were capable to cope with their ailment in a sanguine but engaged way were found to be the ones least affected by their illness while those with the most impaired motor functioning felt the most depressed and misunderstood.

Coping with PD takes place in a social context. The symptoms of PD have strong social implications. Lack of facial movement can interfere with the adequate expression of emotions while the trembling and other motor problems can prompt feelings of social isolation (Strudwick, Mutch and Dingwall-Fordyce, 1990). Social isolation can, in turn, be associated with more severe psychological and cognitive problems (Brod *et al.*, 1998). In fact, the degree of social stress and support which patients experience is a better predictor of depression and anxiety than the severity of the illness (Fleminger, 1991). In yet another study, the degree of social integration and perceived social support were associated with active coping but not with depression (Ehman *et al.*, 1990).

In sum, the coping skills of patients with PD may be limited by the characteristics of their illness while their quality of life also depends on such psychosocial factors as coping and social support. The aim of the present study is to increase our knowledge of the way in which PD affects the life of patients and to clarify the roles of coping and social support in adaptation to Parkinson's Disease. A substantial number of patients with PD were interviewed within a single year. It was hypothesised that coping and social support, in addition to the symptoms of the disease itself, would affect the quality of a PD patient's life. Active coping and social support were expected to be related to a higher quality of life. Passive coping, emotion-focused coping, coping by avoidance and negative social interactions were expected to be related to a lesser quality of life.

METHOD

Subjects

Patients could request a questionnaire through an advertisement in the magazine of the PD disease patient organisation in The Netherlands. This magazine is sent to 5300 subscribers. A total of 115 patients applied for a questionnaire, and 107 completed questionnaires were

returned. One questionnaire had too many missing values and was therefore omitted. The final sample consisted of 106 subjects, almost 85% of the subjects were prepared to participate in the follow-up research. The second measurement (one year later) resulted in 75 usable questionnaires, i.e., 71% of the original sample.

Of the total sample, 54% were female. The ages varied between 44 and 87 years, with a mean age of 63 years and a standard deviation of 9.69 years. The sample is comparable to other samples of PD patients (see Table 1). Most of the subjects were married (73%) and living with their partners (71%). The educational level ranged as follows: 15% had less than a secondary school education, 38% had a secondary school education, 40% had a college education, and 7% had an unknown education. Only 3% of the subjects worked full time, 9% worked part-time, 22% could not work, 45% were retired and 21% were housewives. The diagnosis had been made 20 years previously for 5% of the respondents, between 10 and 20 years for 25%, between 5 and 9 years for 29%, between 1 to 4 years for 38% and less than one year for 3%.

Patients indicated their symptoms on a list with 8 symptoms and could write down additional symptoms beyond those in the list. Bradykinesia was the most common symptom: 78% of the subjects suffered from it; 71% suffered from stiffness and 64% from trembling; 51% had posture problems; 49% had problems with the initiation of movement; 35% complained of muscle weakness; 35% complained of speech problems and 34% complained of an expressionless, mask-like face. Other symptoms were reported by 37% of the respondents. The most frequently mentioned symptoms among these were writing difficulties (6%), too much saliva (6%), fatigue (5%), superfluous movements (4%), difficulties with turning over in bed (4%), bladder problems (3%) and muscular pain (2%). Patients exhibited a mean of 4.14 PD symptoms ($SD = 1.86$, range 0–8).

Measures

Coping was measured using the abbreviated version of the *Utrecht Coping Questionnaire* (UCL) (Schreurs, Van De Willige, Tellegen and Brosschot, 1993). The UCL is a generic measure of coping applicable to stressors in general or to a given situation. The subjects were asked to respond in terms of their disease. The UCL measures seven coping strategies: active coping (e.g., tackle problems immediately) (6 items, $\alpha = 0.85$), distraction seeking (e.g., forget problems by going out) (4 items, $\alpha = 0.63$), seeking social support (e.g., sharing one's worries) (5 items, $\alpha = 0.85$), passive coping (e.g., not feeling able to do something) (5 items, $\alpha = 0.62$), emotion venting (e.g., thinking that others also have difficult times) (2 items, $\alpha = 0.62$), behavioural avoidance (e.g., avoid difficult situations) (3 items, $\alpha = 0.58$) and fostering reassuring thoughts (2 items, $\alpha = 0.55$). The last two scales were excluded due to low reliability. The UCL was completed at time 1.

Received social support was measured by the *Social Support List* (SSL-I) (Kempen and Van Eijck, 1995; Van Sonderen, 1991). The *positive social interactions* subscale refers to the emotional support, instrumental support, esteem support and social companionship received (34 items, $\alpha = 0.92$). In addition, *negative social interactions* are measured by seven items ($\alpha = 0.81$) and refers to negative interactions like being treated coldly or being criticised. The SSL-I was completed at time 1.

Quality of life was measured at time 1 and at time 2 using an abbreviated Dutch version of the *Sickness Impact Profile* (SIP68) (De Bruin, Buys, De Witte and Diederiks, 1994). This

instrument consists of six scales, measuring somatic autonomy (17 items, $\alpha=0.78$), mobility control (12 items, $\alpha=0.82$), mobility range (10 items, $\alpha=0.79$), psychological autonomy and communication (11 items, $\alpha=0.78$), emotional stability (6 items, $\alpha=0.58$) and social behaviour (12 items, $\alpha=0.77$). A higher score indicates greater disfunctioning in the relevant domain. As the internal consistency of the emotional stability sub-scale was found to be below 0.60, this scale was not used.

RESULTS

Quality of life, coping and social support at time 1

Descriptives. Table 2 contains the descriptive statistics. Patients have the most problems with social behaviour followed by mobility control and psychological autonomy and communication. They have the least problems with somatic autonomy. The quality of life in this sample of PD patients is less than in a somewhat younger ($M=57$ years) sample of patients with rheumatic ailments. The scores for the present sample exceed those for the rheumatic sample by 2–3 points on each of the SIP68-subscales (De Bruin *et al.*, 1994).

The patients in our sample appear to cope actively with the stress of their ailment or to seek distraction. Emotion venting is the least used strategy. The patients also have more positive social interactions (i.e., support) than negative social interactions.

Bivariate correlations. In Tables 3 and 4 the correlations of demographic variables, disease characteristics, coping, social support and quality of life are given. Age was not related to symptoms of PD although an older age did relate to greater problems in the physical and social domains. The women had somewhat more problems with mobility control and mobility range than the men while the men had more problems with psychological autonomy and

Table 2 Means and standard deviations of coping, social support and quality of life at time 1 ($N=106$)

Variables	*M*[1] *(SD)*	*Range*
Coping (UCL)		
Active coping	2.49_{a} (0.58)	1–4
Seeking distraction	2.53_{a} (0.52)	1–4
Seeking social support	1.94_{b} (0.53)	1–4
Passive coping	1.85_{b} (0.54)	1–4
Emotion venting	1.62_{c} (0.56)	1–4
Social support (SSL-I)		
Positive social interactions	1.63_{a} (0.39)	1–4
Negative social interactions	1.39_{b} (0.45)	1–4
Quality of life (SIP-68)		
Social behaviour	6.89_{a} (3.18)	0–12
Psychological autonomy and Communication	4.86_{b} (2.96)	0–11
Mobility control	5.42_{b} (3.39)	0–12
Mobility range	2.84_{c} (2.58)	0–10
Somatic autonomy	2.31_{d} (2.65)	0–17

[1] Means within the UCL, SSL-I or the SIP-68 with a different subscript differ significantly at $p<0.000$ by paired t-tests; on the SIP-68 subscales, the paired t-tests were performed on the raw scores divided by the number of items.

Table 3 Correlations of demographic variables, disease characteristics and quality of life at time 1 ($N = 106$)

	1	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*
1. Gender	1.00								
2. Age	0.05	1.00							
3. Duration of disease	–0.01	0.04	1.00						
4. Number of symptoms	–0.09	–0.06	0.31**	1.00					
5. Social behaviour	0.02	0.21*	0.22*	0.38**	1.00				
6. Psychological autonomy and communication	–0.28**	0.08	0.23*	0.45***	0.46***	1.00			
7. Mobility control	0.21*	0.39***	0.25**	0.37***	0.51***	0.37***	1.00		
8. Mobility range	0.18	0.33***	0.20	0.18	0.54***	0.29**	0.42***	1.00	
9. Somatic autonomy	–0.09	0.45***	0.24*	0.26**	0.34***	0.34***	0.39***	0.49***	1.00

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; gender: 1 = male, 2 = female.

Table 4 Correlations of coping, social support and quality of life at time 1 ($N = 106$)

	1	*2*	*3*	*4*	*5*	*6*	*7*
1. Active coping	1.00						
2. Seeking distraction	0.61***	1.00					
3. Seeking social support	0.13	0.14	1.00				
4. Passive coping	–0.14	–0.09	–0.03	1.00			
5. Emotion venting	0.08	0.04	0.20*	0.28**	1.00		
6. Positive social interactions	0.21*	0.28**	0.54***	–0.09	–0.07	1.00	
7. Negative social interactions	–0.05	–0.07	–0.11	0.44***	0.32***	–0.21*	1.00
8. Social behaviour	–0.14	–0.22*	–0.07	0.36***	0.09	–0.01	0.14
9. Psychological autonomy and communication	–0.16	–0.18	–0.05	0.33***	0.04	–0.02	0.29**
10. Mobility control	–0.06	–0.14	0.18	0.30***	0.08	0.08	–0.04
11. Mobility range	–0.11	–0.24*	–0.06	0.31***	–0.08	–0.07	0.10
12. Somatic autonomy	–0.22*	–0.27**	0.02	0.10	–0.05	0.01	0.01

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

communication. Patients with PD for a longer period of time reported more PD symptoms. In fact, longer disease duration and more symptoms were related to a greater number of problems in all domains of functioning.

More active coping and distraction seeking were associated with problems in somatic autonomy. Distraction seeking was also related to mobility range and social behaviour. More passive coping was connected to more problems with mobility range, mobility control, psychological autonomy and communication and social behaviour. The social support measures did not correlate with the quality of life.

Hierarchical regression analyses. Whether the coping and social support variables helped explain the quality of life at the first time of measurement in addition to the demographic and disease characteristics of the patients was examined in hierarchical regression analyses. In Table 5, the results of these regression analyses are summarised. In the first step, the effects of demographic variables were controlled for. In the second step, the disease characteristics were entered. In the third step, the coping and social support variables were entered.

Most of the variance in social behaviour (i.e., 24%) was explained by disease characteristics (i.e. the number of PD symptoms). The coping and social support variables did not add to the explanation of variance in social behaviour. Coping and social support variables, however, play an important role in psychological autonomy and communication where 20% of the variance beyond the 14% explained by demographic and disease characteristics was explained by coping (i.e., by passive coping). Mobility control was clearly explained by age and number of PD symptoms. Although the regression coefficients of passive coping and seeking support were significant, the coping and social support variables did not add to the explanation of variance in mobility control. In addition to the 12% of the variance in mobility range explained by the demographic variables (i.e., by gender) and the 5% explained by disease characteristics, 8% of the variance in mobility range is explained by the coping and social support variables. More passive coping and less distraction seeking were associated with greater mobility-range problems. Somatic autonomy was clearly predicted by age and disease characteristics although the regression coefficients for disease duration and number of PD symptoms did not reach significance. The coping and social support variables did not significantly interact (and the results are therefore not presented in Table 5).

Table 5 Prediction of quality of life at time 1 ($N = 106$)

	Social behaviour		*Psychological autonomy and communication*		*Mobility control*		*Mobility range*		*Somatic autonomy*	
	β	*Adj.*R^2	β	*Adj.*R^2	β	*Adj.*R^2	β	*Adj.*R^2	β	*Adj.*R^2
Step 1 Demographic variables		0.02		0.02		0.16***		0.12**		0.15***
Age	0.14		–0.05		0.28**		0.20		0.40***	
Gender	–0.02		–0.19*		0.14		0.21*		–0.05	
Step 2 Disease characteristics		0.14**		0.14**		0.33***		0.17*		0.24**
Duration	0.13		0.14		0.20		0.12		0.17	
Number of symptoms	0.25*		0.31**		0.30***		0.13		0.19	
Step 3 Coping and support		0.21		0.34**		0.37		0.25*		0.21
Active coping	0.07		0.01		0.05		0.11		–0.08	
Seeking distraction	–0.17		–0.05		–0.10		–0.26*		–0.15	
Seeking social-support	–0.00		0.11		0.22*		0.04		0.08	
Passive coping	0.32**		0.31**		0.24*		0.29*		0.01	
Emotion venting	0.01		–0.03		0.10		–0.08		0.01	
Positive interactions	–0.02		–0.08		–0.16		–0.15		–0.00	
Negative interactions	0.00		0.20		–0.15		–0.06		0.00	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$ (significance of β, F change).

Table 6 Means, standard deviations and correlations for measures of quality of life and number of symptoms at time 1 and time 2 ($N=76$)

Variables	*M1 (SD1)*	*M2 (SD2)*	*r 1,2*
Social behaviour	6.86 (3.02)	6.88 (2.89)	0.81***
Psychological autonomy and communication	4.73 (2.90)	4.59 (2.94)	0.70***
Mobility control	5.43 (3.26)	5.71 (3.13)	0.70***
Mobility range	2.57 (2.51)	2.91 (2.60)	0.75***
Somatic autonomy	2.14 (2.28)	2.43 (2.84)	0.63***
Number of PD symptoms	4.23 (1.82)	4.07 (1.81)	0.65***

*** $p<0.001$.

Quality of life after one year

Those patients who participated in the measurement at time 2 did not differ significantly from those who did not participate (i.e., demographic variables, disease characteristics, coping, social support or quality of life did not differ for the two groups).

Stability. The results presented in Table 6 show that the quality of life for the PD patients studied here was relatively stable over the course of a year. The scores on the SIP-68 subscales at time 1 and 2 did not differ significantly and correlated strongly. The number of Parkinson symptoms was also found to be quite stable over the course of a year.

Bivariate and partial correlations. Table 7 shows the bivariate correlations of the coping and social support variables measured at time 1 with quality of life measured one year later at time 2. Passive coping at time 1 is correlated with mobility control, psychological autonomy and communication and social behaviour at time 2. In addition, active coping and negative social interactions at time 1 are related to psychological autonomy and communication at time 2.

In order to evaluate causal relations of coping and social support for the quality of life, one year later, hierarchical regression analyses were performed on the time 2 quality of life measurements, with the time 1 coping and social support measures as the independent variables entered in step 2, and the time 1 quality of life measures as control variables entered in step 1. As might be expected on the base of the stability of SIP-68 subscales over a year, the variables in step 2 did not add to the explanation of the variance in time 2 SIP-68

Table 7 Correlations of coping and social support measured at time 1 with quality of life at time 2 ($N=76$)

	Social behaviour 2	*Psychological autonomy and communication 2*	*Mobility control2*	*Mobility range 2*	*Somatic autonomy2*
Active coping 1	–0.03	–0.26**	–0.06	–0.15	–0.14
Seeking distraction 1	–0.10	–0.09	0.03	–0.23*	–0.18
Seeking social support 1	–0.04	–0.12	0.18	0.06	0.18
Passive coping 1	0.42***	0.23*	0.25*	0.18	0.04
Emotion venting 1	0.02	–0.09	0.10	–0.18	–0.09
Positive social interactions 1	0.00	–0.11	0.03	–0.08	0.16
Negative social interactions 1	0.15	0.26**	0.05	–0.06	–0.17

* $p<0.05$; ** $p<0.01$; *** $p<0.001$.

subscales above the variance explained by the corresponding SIP-68 subscale at time 1. Accordingly, univariate partial correlations were computed. The partial correlation of active coping at time 1 with psychological autonomy and communication at time 2 remained significant ($r_{part} = -0.29$, $p = 0.012$) after controlling for psychological autonomy and communication at time 1. None of the other partial correlations reached significance.

DISCUSSION

The impact of Parkinson's Disease extends beyond the suffering of mere symptoms. Physical, psychological and social functioning are clearly affected. PD patients encounter more problems in these domains than patients with rheumatic ailments (De Bruin *et al.*, 1994). PD patients have the most difficulties with social functioning, followed by mobility control and psychological autonomy and communication. Recently, a number of disease specific instruments have been developed to measure the subjective of experiences of patients suffering from PD (Brod *et al.*, 1998; De Boer, Wijker, Speelman and De Haes, 1996; Jenkinson, Peto, Fitzpatrick, Greenhall and Heyman, 1995). These studies, which were not published at the start of our study, show patients to be more troubled by motoric symptoms and to rate such symptoms as more severe than problems in the cognitive, psychological, emotional and social domains (Brod *et al.*, 1998; De Boer *et al.*, 1996). In other words, such generic measures of the quality of life as the SIP-68 may underestimate the impact of specific Parkinsonian motoric symptoms. It is therefore to be recommended that a disease-specific quality of life measure be used in addition to a generic instrument.

In comparison with other chronic ailments, PD manifests itself at a relatively greater age. The aging process may therefore be superimposed on the suffering of PD symptoms, and this appears to be reflected in our results. Greater age was related to diminished physical functioning but not to diminished psychological or social functioning in the sample of PD patients studied here. Moreover, loss of somatic autonomy seems to be more an effect of aging than of PD while PD symptoms and aging both affect mobility control. The relation between a longer disease duration and a lower quality of life also appears to be a result of aging as disease duration loses its connection to the quality of life when age is controlled for.

The number of PD symptoms is an important predictor of the domains in which patients may have the most problems functioning, that is, mobility control, psychological autonomy and communication and social behaviour. The number of PD symptoms is also related to not only psychological autonomy and communication but also social behaviour one year later although these relations disappear when previous functioning is controlled for. Nevertheless, our results clearly point to the importance of symptom management in PD.

The patients in our study were found to use more active than passive coping strategies to deal with the stress of their ailment. This is fortunate as more passive coping is consistently related to more problems in all domains of functioning, with the exception of somatic autonomy. These findings are in line with the findings of other studies concerned with the coping of PD patients (Brod *et al.*, 1998; Dakof and Mendelsohn, 1989; Ehman *et al.*, 1990). Nevertheless, the effects of passive coping are not so strong that they particularly affect the functioning of patients after one year. Conversely, active coping did not relate to the physical, psychological or social functioning of the patients at time 1 but was positively related to psychological functioning and communication one year later.

Although coping appears to mediate the relation between symptoms and quality of life, the connections were weak in the present study. The relatively distant and stable outcome measure may be the reason for such a weak relation. The SIP-68 counts the number of disabilities in a number of different domains but many of the disabilities may actually be irreversible and thus not amenable to coping behaviours. More sensitive outcome measures such as mood or daily fluctuations in physical adjustment may be required to establish the effects of particular coping strategies on the daily life of the chronically ill (Folkman, 1992). A study by MacCarthy and Brown (1989) showing coping by problem solving to be related to positive affect partly confirms this line of reasoning.

Contrary to our expectations, the coping strategy of seeking social support and the support received by the patients did not affect their quality of life. Negative social interactions were, however, related to problems with psychological functioning. The direction of the connection is nevertheless not clear since this relationship was characterised only by the cross-sectional data. Studies of other chronic ailments, however, suggest a bi-directional influence, with more negative interactions leading to worse functioning and vice versa (see Schreurs and De Ridder, 1997).

Our results are in contrast to the majority of other studies on PD which show positive relations between greater social support and better functioning (Brod *et al.*, 1998; Fleminger, 1991; MacCarthy and Brown, 1989; Speer, 1993). One explanation may be that a minimal amount of social support is necessary to cope with PD and that an extreme lack of support may thus have detrimental effects (Gove, Briggs Style and Hughes, 1990). Brod *et al.* (1998) indeed found social isolation to be related to more severe psychological and cognitive problems, but the sampling method of this study makes it unlikely that socially isolated patients will participate as they are not very likely to be members of a patient organisation. In this connection, it should be noted that the subject sample in the present sample was self-referred. It is very likely that members of a patient organisation who actively apply to participate in research are also those who cope actively with the stress of their illness. Similarly, severely depressed patients are not very likely to request a questionnaire through an advertisement in a magazine of a patient organisation. In sum, the sample of the present study probably consists of patients who are adapting relatively well to their ailment.

The importance of symptom management has practical implications. Symptom management is not only the concern of health-care providers. Larson (1994, p. 274) stated: "Successful symptom management requires a patient-family-clinician partnership". In PD patients and caregivers, moreover, the perception of control over symptoms is more important to their well being than actual control over disease progression (Wallhagen and Brod, 1998).

This means that health-care providers should also aim in their interventions at enhancing the capacity of patients and families to manage the daily symptoms of PD. Although many symptoms of PD are difficult to control, self-management of PD symptoms is not totally precluded. First, patients can be helped to make better use of the beneficial effects of medication. Moreover, physical exercise may alleviate posture problems and speech therapy can be helpful in dealing with communication problems (Pearce and Jones, 1994). Further, education and training in coping skills, stress management and cognitive symptom management techniques can reduce psychological and social difficulties. Self-management programs in which patients learn to cope as actively as possible with daily symptoms and diminishing feelings of helplessness have been shown to be effective for PD-patients (Ellgring, Seiler, Nagel, Perleth, Gasser and Oertel, 1990) as well as for older chronically ill persons (Lorig, Sobel, Stewart, Brown, Bandura, Ritter, Gonzalez, Laurent and Holman, 1999).

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