

# Spasmodic torticollis – a multicentre study on behavioural aspects III: psychosocial changes and coping

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Psychosocial changes in spasmodic torticollis (ST) affect predominantly social life, professional life and psychological well-being. Concerning social life, 84.6% of the patients felt that they attracted considerable public attention due to their neurological illness and 65% had reduced participation in social events. A substantial number of patients had retired from professional activities; others felt severely impaired in their working capacity. The psychosocial sequelae in ST, however, seemed to depend less on the neurological signs *per se* than on the physical symptoms and on coping. Depressive coping in particular emerged as a predictor of psychosocial distress.

**Keywords:** Spasmodic torticollis – Neurologic symptoms – Coping – Psychosocial changes

## INTRODUCTION

In spite of the improvement in treatment by the use of botulinum toxin within recent years, spasmodic torticollis (ST) takes a chronic course in the majority of patients. The visible, sometimes even disfiguring, symptomatology may entail severe psychosocial changes and require considerable efforts in coping.

As reported in the preceding paper (Heinen *et al.*, 1996), compared to a control group with cervical spondylosis, Jahanshahi and Marsden (1988, 1990a,b) found increased depression scores in ST. The authors considered the depressive symptoms to be related to disfigurement (see Scheidt *et al.*, 1996). Halbgewachs and Aschoff (1992), Matthews *et al.* (1978) and others have also described negative effects of ST on social, professional and everyday life. In addition to the functional impairment affecting everyday and professional life, profound changes were reported to occur in social relations. According to Rentrop and Straschill (1982) 28 of the 37 patients in their sample indicated almost complete retreat from public and social relationships and limitation of their social contacts to the immediate family.

As mentioned earlier, few studies so far have investigated coping strategies in ST. Jahanshahi (1991) reported that cognitive and emotion-focused coping strategies dominate in ST, compared to instrumental ways of coping (in the Ways of Coping Checklist by Folkman and Lazarus, 1980). The coping strategies mainly applied were threat-minimization, wishful thinking and cognitive restructuring; by contrast, positive reappraisal, religious faith and instrumental coping were less frequent (Jahanshahi, 1991). Wishful thinking and religious faith in that study were related to depression. The results demonstrate that coping may be relevant in ST not only to social adjustment but also to psychological dysfunction.

In this paper three questions outlined in the first paper in this series (see Scheidt *et al.*, 1996) will be addressed. What are the predominant psychosocial changes due to ST, if any, and what areas of life (professional, family, social and everyday life) are mainly affected? Are these psychosocial changes related to specific features of the neurological condition? What coping mechanisms are used in ST and do

psychosocial changes depend on specific patterns of coping?

## RESULTS

### Psychosocial changes

The psychosocial changes are described on item-level first, reporting on each area of life separately. The frequencies summarize two or more rating categories, which refer to the five-point rating scale used in the Freiburg Questionnaire for Dystonia (FQD) (see Scheidt *et al.*, 1996).

**Professional life.** Changes in this area are reflected in a large number of retirements which had taken place in 56 patients (23.4% of the total sample). Thirty-seven patients (14.4% of the total sample) were on sick leave at the time of the study. Of the 119 patients who were still working, 51.3% felt severely or very severely impaired in their professional activities. A comparable proportion (50.5%) had severe or very severe doubts concerning their future professional career; 33.1% of the patients reported financial losses as a result of their disease (categories 3–5). Of the total, 53.4% had considerably curtailed their contacts with colleagues (categories 3–5).

**Everyday life.** In everyday life, 64.4% of the patients showed disabilities in performing their household chores (categories 3–5), and 51% in undertaking spare-time activities such as reading or watching television (categories 3–5). Driving a car was affected in 59.5% (categories 3–5). Of the patients 55.3% felt disabled as pedestrians (categories 3–5) or using public transport (42.4% categories 3–5).

**Social life.** Disfigurement plays a particular role in social life. Of the patients 84.6% felt that they attracted considerable public attention (categories 3–5). Sixty-five per cent had reduced their participation in public events (categories 4 and 5), premorbid contacts with friends and acquaintances had decreased in 19.2% (categories 4 and 5). Of the patients 79.9% reported being affected in spare-time activities involving social contacts (categories 3–5). Due to the changes in their social life, 49.6% of the patients felt socially isolated (categories 3–5).

**Family life.** Compared with the other areas, relatively minor changes occurred in the patients' family life. These affected mainly family events (28.9% categories 4 and 5) and changes in the distribution of tasks within the family (23.4% categories 4 and 5).

However 25.5% reported a moderate to very severe deterioration of the family atmosphere; and 21.7% of the families were moderately to very severely affected by financial losses.

**Psychological well-being.** The patients were asked whether their psychological well-being had changed compared to the time before the beginning of their illness. The following percentages refer to the rating categories 3–5: depression (63.6%), feeling of reduced attractiveness (64.4%), irritability (54.9%), anxiety (62.6%), feeling less assertive (55.5%).

As described in our first paper (Scheidt *et al.*, 1996), the individual ratings of the different areas were summarized to item-standardized scales. The mean values of the scales indicate roughly the severity of the psychosocial changes in the respective area of life. As can be seen from Fig. 1 three areas of life are particularly affected. These are *social life* (1.97, SD = 0.9), *professional life* (1.82, SD = 0.9) and *psychological well-being* (1.90, SD = 0.9), whereas everyday life and family life are slightly less impaired.

Women felt more severely disabled in daily life than men ( $p < 0.01$ ); family life was reported by men to be more severely affected ( $p < 0.05$ ). No significant differences between the sexes were found in any other area.

Psychosocial changes do not affect all patients equally. Referring to social life for example, 34% of the patients reported no or very minor changes (categories 1 and 2) in their participation in social events and 50.4% did not feel socially isolated at all due to the disease.

### Coping

Figure 2 shows mean values and standard deviations of the preferred coping strategies in the Freiburger Questionnaire for Coping (FKV). *Active problem-focused coping* was most frequent.

This coping strategy includes activities and attitudes such as planned problem solving, search for information, will and stamina but also an attitude of compensatory life enjoyment. *Self-distraction* and *encouragement* ranked second. These include strategies of cognitive distraction as well as positive self-instruction. *Religious faith* and *search for meaning* ranked third. Items of this scale ask about comfort found in religious faith, acceptance of the disease as a fate, the search for meaning in life and the pursuit of altruistic ideas.

*Depressive coping* as well as *minimization* and *wishful thinking* were equally frequent. Depressive coping

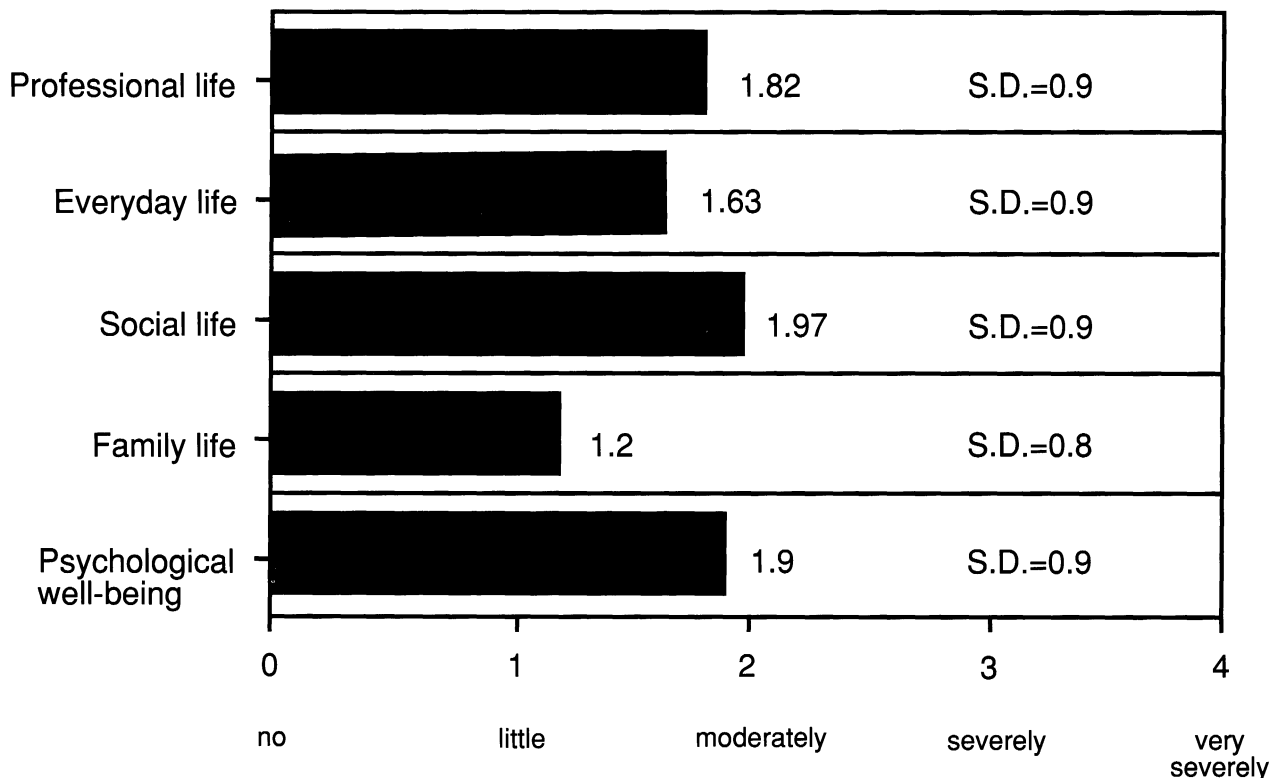


FIG. 1. Psychosocial changes in different areas of life. Mean scores and standard deviations.

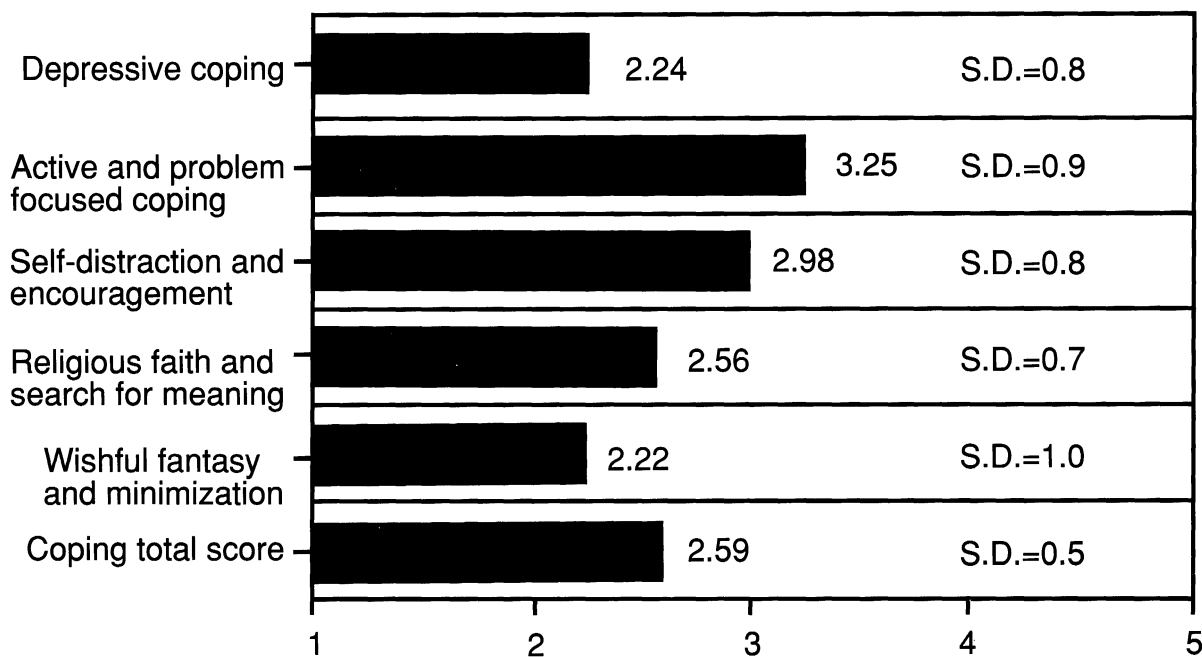


FIG. 2. FKV coping scales, mean scores and standard deviations.

describes cognitive-emotional elements of depression. The scale minimization and wishful thinking comprises cognitive defence strategies such as not wanting

to recognize a painful experience or to minimize its significance.

Female patients applied active problem-focused

coping strategies more often than male patients ( $p < 0.5$ ); however the total coping activity did not differ significantly between the sexes.

**Interrelations of the measures.** Table I shows correlations between psychosocial changes, demographic variables, signs, symptoms and coping. The correlations between *symptoms* (pain, muscle tension and head deviation) and *psychosocial changes* are highly significant throughout. The correlations between *signs* and *psychosocial changes* are markedly weaker. However retro/anterocollis shows a substantial correlation with changes in those areas of life which specifically require functional capacities (e.g. professional and everyday life). This may indicate that retro/anterocollis is more functionally disabling than rotational or even tilting torticollis. The correlations between *demographic variables* and *psychosocial changes* are negligible, whereas the correlations between *coping strategies* and *psychosocial changes* show close associations between depressive coping and psychosocial changes in all areas of life.

Table II shows the correlations between coping, demographic variables, signs and symptoms. Age correlates significantly with two of the coping strategies, namely *religious faith* and *search for meaning*. The signs do not correlate with coping at all. The correlations between symptoms and coping are low. However, some significant positive correlations emerge with depressive coping.

**Predictors of psychosocial changes.** In order to investigate predictors of psychosocial changes, a stepwise multiple regression analysis was calculated. Independent variables were the signs (deviation of the head in different planes and the TSUI-index, the symptoms (deviation of the head, muscle tension, tremor and pain) and coping (five coping strategies).

The five area-of-life-scales (sum scores) were the criterion variables; missing data were pair-wise excluded. Table III shows the results. The predictive power of the equations ranges between  $r^2 = 0.33$  for family life and  $r^2 = 0.50$  for everyday life.

In those areas where functional impairment is of particular importance, the symptoms *pain* and *muscle tension* accounted for the highest variance and enter the equation first, whereas *depressive coping* emerged as the most important factor for changes in family and social life and for psychological well-being.

The *deviation of the head* (self-reported) entered four equations. This variable seems particularly important for *social life*, accounting for 15% of the variance.

The *signs* played only a minor role for the psychosocial changes accounting for a low variance in two equations.

In summary, psychosocial changes in ST seem to depend more on symptoms than on signs. With regard to coping, a depressive coping style in particular contributes to the experience of life as more severely impaired due to the illness.

## DISCUSSION

The results of the study may be summarized under two categories, coping and psychosocial changes.

### Coping

The majority of ST patients apply active, problem-focused coping strategies and strategies such as self-distraction and encouragement, religious faith and search for meaning.

Other studies reported a preference of cognitive and emotion-focused coping over active instrumental coping styles in ST (Jahanshahi, 1991). Different rating instruments may account for the discrepant results. Compared to those studies using the same questionnaire (FKV), for example studies on cancer, end-stage renal disease and multiple sclerosis, the coping strategies in ST equal those of other patient groups suffering from chronic illnesses (Muthny *et al.*, 1992).

The correlations of coping strategies with sex, age and the severity of illness reported in the literature differ (Normann and Kordy, 1991; Muthny, 1992; Voll *et al.*, 1992). In agreement with Jahanshahi (1991) we found that female torticollis patients generally used more coping strategies than men, but this was statistically significant only for one coping style, namely active, problem-focused coping. *No significant correlations were found between the severity of the neurological signs and coping.* This suggests that the preferred coping strategies are not determined by characteristics of the neurological condition.

However substantial correlations emerged between the neurological symptoms and coping, most pronounced for *pain* and *depressive coping*. This confirms the results of Jahanshahi (1991), who also reported a significant correlation between pain and maladaptive coping. Although in both studies the correlations between dysfunctional coping strategies and pain were not high (0.30 and 0.35 respectively), it can be concluded that pain and depressive coping are likely to interact and facilitate each other.

As has been reported in other studies on coping (Muthny *et al.*, 1992; Harrer *et al.*, 1993), religious faith and search for meaning are more widely used

TABLE I. Correlations between psychosocial changes (scales of the FQD) signs (neurological assessment) symptoms (self-reported) and coping (FKV)

	Professional life	Everyday life	Family life	Social life	Psychological well-being
Age	0.08	0.09	-0.05	-0.08	-0.05
Age at onset	0.14	0.17**	-0.00	-0.04	-0.09
Duration	-0.13	-0.02	-0.04	-0.01	0.07
Neurological signs					
TSUI-index	0.05	0.15*	0.27***	0.12	0.05
Rotation	-0.05	-0.12	-0.06	-0.07	-0.08
Laterocollis	-0.00	0.13	0.16*	0.14*	0.06
Antero-retrocollis	0.26**	0.29***	0.21**	0.11	0.01
Neurological symptoms					
Deviation head	0.50***	0.46***	0.37***	0.47***	0.31***
Muscle tension	0.50***	0.56***	0.38***	0.47***	0.35***
Tremor of head	0.27**	0.09	0.13*	0.25**	0.29***
Pain	0.57***	0.55***	0.38***	0.43***	0.34***
Coping					
Depressive coping	0.45***	0.33***	0.40***	0.49***	0.65***
Active and problem focused coping	0.22*	0.27***	0.09	0.11	0.13*
Self-distraction and encouragement	0.12	0.18**	0.02	-0.01	-0.01
Religious faith and search for meaning	0.27**	0.29***	0.16*	0.10	0.10
Wishful thinking and minimization	0.27**	0.18**	0.18**	0.20**	0.31***
Coping total score	0.40***	0.41***	0.33***	0.32***	0.39***

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p > 0.001$ . The correlations between psychosocial changes and the neurological symptoms are highly significant throughout, whereas the correlations between psychosocial changes and the neurological signs are weak.

TABLE II. Correlations between coping (FKV), demographic variables, signs (neurological assessment) and symptoms (self-reported)

	Depressive coping	Active and problem focused coping	Self-distraction and encouragement	Religious faith and search for meaning	Wish-fulfilling fantasy and minimization	Coping total score
Age	-0.15**	0.11*	0.03	0.26***	0.05	0.09
Age at onset	-0.17**	0.09	-0.03	0.15**	0.07	0.03
Duration	0.00	0.02	0.05	0.16**	-0.06	0.06
Neurological signs						
TSUI-index	0.02	0.05	0.10	0.10	0.10	0.10
Rotation	-0.03	0.04	0.08	0.03	-0.01	0.01
Laterocollis	-0.06	0.00	-0.04	0.14	0.05	0.02
Antero-retrocollis	0.06	-0.12*	0.00	0.06	0.06	0.10
Neurological symptoms						
Deviation head	0.18**	0.03	0.00	0.13*	0.08	0.13
Muscle tension	0.22***	0.19**	0.09	0.16**	0.18**	0.26***
Tremor of head	0.16**	0.14*	0.09	0.03	0.03	0.19**
Pain	0.30***	0.21***	0.11*	0.16**	0.09	0.29***

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ . Significant correlations between depressive coping and the neurological symptoms, no correlations however, with the neurological signs.

TABLE III. Multiple regression analysis with psychosocial changes (scales of the FQD) as dependant variables

Criterion variables	Predictor variables	Betaweight	r <sup>2</sup>
Professional life	1. Pain	0.36	0.33
	2. Depressive coping	0.29	0.41
	3. Deviation head	0.29	0.49
Everyday life	1. Muscle tension	0.22	0.31
	2. Pain	0.24	0.37
	3. Antero-retrocollis	0.20	0.42
	4. Religious faith and search for meaning	0.18	0.46
	5. Depressive coping	0.15	0.48
	6. Deviation head	0.16	0.50
Family life	1. Depressive coping	0.31	0.16
	2. Deviation head	0.18	0.25
	3. TSUI-index	0.22	0.30
	4. Muscle tension	0.19	0.33
Social life	1. Depressive coping	0.39	0.24
	2. Deviation head	0.27	0.39
	3. Muscle tension	0.23	0.43
Psychological well-being	1. Depressive coping	0.39	0.42
	2. Muscle tension	0.18	0.47
	3. Tremor of head	0.16	0.49

Neurological symptoms rather than neurological signs predict psychosocial changes in different areas of life.

by older patients. Our data confirm a positive correlation between age and these two coping strategies.

### Psychosocial changes

The results of the study show that ST may entail severe psychosocial changes. *Social life* in particular is affected. This is in line with other reports in the literature (Matthews *et al.*, 1978; Rentrop and Straschill, 1982; Halbgewachs and Aschoff, 1992; van Herwaarden *et al.*, 1994). In contrast, family life seems slightly less impaired. However, psychosocial changes do not occur in all patients equally. The question arises to what factors differences might be attributed.

Although *depressive coping* is not very common among ST patients as compared to active, problem-focused coping, it is of particular importance in predicting psychosocial changes: in the regression analysis, depressive coping entered in all equations and accounted for the highest variance for three areas of life, psychological well-being, social life and family life. The neurological symptoms turned out to be important predictors too, entering all equations and accounting for the highest variance in professional life and in everyday life. In contrast the neurological signs were only of minor significance in predicting psychosocial changes.

Psychosocial changes do not occur automatically as a consequence of ST (Rondot *et al.*, 1991; Halbgewachs and Aschoff, 1992). Coping strategies (Halbgewachs and Aschoff, 1992) and the "personal manage-

ment of the disease" (Rondot *et al.*, 1991) are important modulating factors. Social support, locus of control and causal attribution (Beutel and Muthny, 1988) as well as personality traits, none of which has been included in this study, may be of relevance too.

The results confirm the importance of coping for psychosocial adjustment in chronic diseases (Felton and Revenson, 1984; Felton *et al.*, 1984; Friedman *et al.*, 1988). However, it is important to point out that coping and psychosocial adjustment are interdependent (Heim *et al.*, 1983; Lazarus *et al.*, 1985). There is no unidirectional causal relationship between the two.

A more extensive analysis of the links between coping processes and psychosocial adjustment as described in various theoretical models (Heim, 1988; Lazarus and Folkman, 1984) is beyond the scope of this study. Investigation of these issues would require other than cross-sectional data. Nevertheless the presented results provide sufficient evidence to assume a rather close correlation between coping and psychosocial changes in ST.

Concerning treatment it may be concluded that the subjective awareness of the physical symptoms is strongly influenced by psychological processes (Weisenberg, 1977). Psychotherapeutic treatment might help to improve the patients' management of their symptoms and thus may result in a better social adjustment. Changes in maladaptive coping strategies may help to reduce the psychosocial changes. The

importance of coping for psychosocial adjustment therefore supports the argument for psychotherapy in ST.

Several authors have pointed out that ST patients applying "adaptive" coping strategies show a more favourable course than those applying maladaptive coping strategies (Rentrop and Straschill, 1982; Witzmann *et al.*, 1984; Marten and Thomä, 1988; Halbge-wachs and Aschoff, 1992). A concentration of treatment on coping might therefore help to improve not only the psychosocial adjustment but also the course of the disease.

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