

## **CARERS' COPING WITH POST-ONSET PERSONALITY AND PHYSICAL CHANGES IN PATIENTS WITH NEUROLOGICAL DISORDERS<sup>#</sup>**

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*Coping plays an important role in a person's adjustment to stress. This study examined carers' coping with post-onset personality and physical changes in patients with neurological disorders. 4-8 months post-onset 112 carers completed the Ways of Coping Questionnaire (Folkman & Lazarus, 1988), both in relation to personality and physical changes in patients. It was found that carers employed a variety of strategies to cope with personality changes compared to physical changes. Carers depended more on emotion-focused strategies while coping with personality changes, whereas more problem-focused strategies were used to cope with physical changes. It was concluded that the way a carer copes depends on the type of post-onset changes manifested by a patient.*

Over the years, the term coping has been used interchangeably with concepts such as mastery, defense, and adaptation (White, 1974). A number of working definitions have been proposed by researchers (Fleming, Baum, & Singer 1984; McCubbin & McCubbin, 1987; Pearlin & Schooler 1978; Revenson & Felton, 1989). Furthermore, there are different models which define coping. Previously there had been two basic models to the conceptualization of coping, i.e., 'animal model' and 'ego or psychodynamic model'. Both models lack popularity because of the unavailability of empirical evidence to support their conceptualization of coping as well as due to other limitations inherent

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in these models (Cohen & Lazarus, 1973; Folkman & Lazarus, 1980, 1988; Lazarus & Folkman, 1984, 1987).

During the 1970s the process or cognitive model of coping began to emerge (Billings & Moos, 1981; Folkman & Lazarus, 1980; Lazarus, 1966; Lazarus & Launier, 1978; Moos & Tsu, 1977; Pearlin & Schooler, 1978; Stone & Neale, 1984). The cognitive model has been acknowledged as the most comprehensive model of stress, coping, and adaptation (Coyne & Smith, 1991; Slavin, Rainer, McCreary, & Gowda, 1991). This approach conceptualizes coping as the cognitive and behavioural efforts of the individual to manage (reduce, minimize, master, or tolerate) the internal or environmental demands of person-environment transactions that are appraised as taxing or exceeding the resources of the individual (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus & Launier, 1978; Moos & Billings, 1982; Moos & Tsu, 1977).

Coping involves a variety of thoughts and actions, and, therefore, is a dynamic process. Depending on the function of coping, researchers have made a distinction between active (e.g., vigilant, problem-focused), or avoidant (e.g., denial) types of coping (Billings & Moos, 1981; Lazarus & Folkman, 1984; Menaghan, 1983). Coping within the framework of the cognitive model has two primary functions (Lazarus & Folkman, 1987): (i) to change the actual terms of the troubled person-environment relationship, referred to as problem-focused coping, and (ii) to regulate emotional distress, i.e., emotion-focused coping. Problem-focused coping helps an individual to handle the environmental transaction, whereas emotion-focused coping aims at reducing the affective, visceral, and motor disturbances that distress the person. Each function is served by a number of thoughts and actions. Based on two basic functions of coping, Folkman and Lazarus (1988) specified eight coping strategies in their Ways of Coping (WOC) Questionnaire. Problem-focused strategies included confrontive coping and planful problem-solving; and emotion focused scales included distancing, seeking social-support, self-control, escape-avoidance, and positive-reappraisal (e.g., Sistler, 1989).

The type of coping used by an individual varies depending on numerous factors. Emotion-focused coping is depended on when direct action is difficult to take or when a person is unable to manage successfully the environmental demands, whereas problem-focused coping is more relied upon when the encounter is changeable. In highly stressful situations, the individual utilizes more emotion-focused coping and fewer problem-focused strategies (Lazarus & Folkman, 1984). It is

argued that in the presence of high levels of stress an individual's capabilities for both information processing and problem solving get impaired, and as a consequence the individual depends more on emotion-focused coping. Furthermore, the increased emotional distress in the face of high stress may require the use of tension reducing strategies (Anderson, 1977; Edhe & Holm, 1992; Lazarus & Folkman, 1984; Terry, 1991).

Several studies carried out on head injury and stroke have demonstrated that personality and behaviour changes are more stressful and burdensome for relatives (e.g., Brooks, 1984,1991; Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Carnwath & Johnson, 1987). It has been suggested by Lazarus and Folkman (1984) that excessive stress or threat interferes with a problem-focused form of coping through its adverse effect on cognitive functioning and the capacity for information processing. Others have suggested that, at high levels of stress, emotion-focused coping becomes predominant.

The present study was designed to examine the ways in which carers cope with post-onset personality and physical changes in patients with neurological disorders. In this study carer was defined as a person (relative or a friend) who assumed the main responsibility to look after the patient's every day needs. Considering personality and behaviour changes as more burdensome for relatives than physical changes, it was hypothesized that carers would use more coping strategies, particularly emotion-focused strategies and would use less problem-focused strategies to cope with personality changes than with physical changes.

## METHOD

### Sample

112 carers of patients with neurological disorders were the participants of the study. The patients were recruited from the King's College Hospital (London), and two Rehabilitation Units at the Surrey County, England. Patients provided their carers' addresses, who were later on mailed the questionnaires.

There was almost an equal number of male ( $n= 55$ ) and female ( $n=57$ ) patients. Most of them were married (82%) and they ranged in age from 16-75 years ( $M= 54$ ;  $SD= 17.2$ ). The majority of them had suffered a stroke (71%), some of them had head injury (16%), and few had suffered other neurological diseases, such as, Guillian-Barre Syndrome, Encephalitis, and Meningitis (13%). Carers were mainly females (67%), ranging in age from 25-79 years ( $M= 52.2$ ;  $SD= 14.4$ )

and majority of them were married (83%). Sixty-eight carers were spouses, and 15 were parents. The remaining were either children ( $n=4$ ), siblings ( $n=10$ ), other relatives ( $n=10$ ), or friends of the patients ( $n=5$ ). Most of them reported themselves as healthy (85%) and only a few reported health problems, such as, tension and anxiety ( $n=4$ ), diabetes ( $n=4$ ), and heart related diseases ( $n=7$ ).

A total of 352 patients were mailed the questionnaires and 193 patients passed on the questionnaires to their carers. Of those, 155 carers responded; of whom 27 did not want to participate and 16 questionnaires did not qualify the analysis. Thus, the response rate was considered to be 72% (155 out of 193).

## **Instrument**

### *Ways of Coping Questionnaire*

WOC Questionnaire (Folkman & Lazarus, 1988) was used to assess carers' coping with post-onset personality and physical changes in patients. It consists of 66 items. The factor analysis revealed that the questionnaire comprises eight coping strategies: Confrontive Coping, Planful Problem-solving, Distancing, Seeking Social-support, Self-control, Escape-avoidance, Accepting Responsibility, and Reappraisal. The respondent has to respond on a 4-point scale the extent to which he/she uses a particular strategy. The WOC Questionnaire has been successfully used in related studies (e.g., Neundorfer, 1991; Thompson, Zeman, Fanurik, & Sirotkin-Roses, 1992; Vitaliano, Maiuro, Russo, & Becker, 1987).

## **Procedure**

In a transactional design, 112 carers of patients with neurological disorders were asked to complete the WOC Questionnaire twice; once in relation to personality changes in patients and, once in relation to physical changes in patients. The assessment was carried out 4-18 months post-onset.

## **RESULTS**

### **Carers' Coping with Personality and Physical Changes in Patients**

Two separate multivariate analyses of variance (within-subject design: one for personality changes; and one for physical changes)

were performed to examine the ways carers coped (using eight coping strategies) with patients' post-onset changes. Analyses revealed significant differences between carers' use of different coping strategies, both in relation to personality (Hotellings  $T^2 = 23.54$ ,  $p < .001$ ) as well as physical changes (Hotellings  $T^2 = 46.46$ ,  $p < .001$ ) in patients.

Table 1

*A posteriori difference between carers' mean scores on different coping strategies with regard to personality changes (Tukey Test Results)*

	Coping Strategies	Mean Scores	I	II	III	IV	V	VI	VII	VIII
			.67	.73	.91	.83	.93	.79	.92	.45
I	Confrontive	.67		.06**	.24**	.16**	.26**	.12**	.25**	.22**
II	Distancing	.73			.18**	.10**	.20**	.06**	.19**	.28**
III	Self-control	.91				.08**	.02	.12**	.01	.46**
IV	Seeking Social Support	.83					.10**	.04	.09**	.36**
V	Escape Avoidance	.93						.14**	.01	.48**
VI	Problem Solving	.79							.13**	.34**
VII	Reappraisal	.92								.47**
VIII	Accepting Responsibility	.45								

Note: Tukey *a* test:  $p < .05 = 0.048$ ,  $p < .01 = 0.054$ ; \* $p < 0.05$ ; \*\* $p < 0.01$ .

Table 2

*A posteriori difference between carers' mean scores on different coping strategies with regard to physical changes (Tukey Test Results)*

	Coping Strategies	Mean Scores	I	II	III	IV	V	VI	VII	VIII
			.66	.75	.92	.86	.91	.81	.95	.40
I	Confrontive	.60		.09**	.26**	.20**	.25**	.15**	.29**	.26**
II	Distancing	.75			.17**	.11**	.16**	.06**	.20**	.35**
III	Self-control	.92				.06**	.01	.11**	.03	.52**
IV	Seeking Social Support	.86					.05**	.05	.09**	.46**
V	Escape Avoidance	.91						.10**	.04	.51**
VI	Problem Solving	.81							.14**	.41**
VII	Reappraisal	.95								.45**
VIII	Accepting Responsibility	.40								

Note: Tukey *a* test:  $p < .05 = 0.046$ ,  $p < .01 = 0.054$ ; \* $p < 0.05$ ; \*\* $p < 0.01$ .

A series of Tukey tests (Cohen & Holliday, 1982) were performed as a *post-hoc* procedure for examining the differences between specific coping strategies used by carers (Tables 1 and 2). Regarding both types of changes, the same patterns of results was revealed. Coping by the way of accepting responsibility was the least used coping strategy. Confrontive coping was employed less than the rest of the coping strategies. Distancing was used less than Self-control, Seeking Social-support, Escape-avoidance, Problem-solving, and Reappraisal. Carers sought more social-support and used less problem-solving compared with exercising Self-control. Escape-avoidance and Reappraisal were employed more than Seeking Social-support. Carers used less Problem-solving than Reappraisal.

### Carers' Coping with Personality Changes as Opposed to Physical Changes

To compare carers' coping with personality changes with that of physical changes, paired *t*-test were carried out to evaluate difference in carers' scores on eight coping scales and the total coping score on the WOC. The results presented in Table 3 indicate that carers sought less Social-support, used less Problem-solving and Reappraisal, and accepted more Responsibility to cope with patients' personality changes than physical changes. Carers scored higher on the WOC in relation to personality changes than to physical changes.

Table 3

*Differences between carers' coping with personality changes and physical changes in patients*

Coping Strategies		Type of Changes				<i>t</i>
		Personality ( <i>n</i> = 106)		Physical ( <i>n</i> = 108)		
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
I	Confrontive	0.67	0.08	0.66	0.09	1.25
II	Distancing	0.73	0.10	0.74	0.11	-1.31
III	Self-control	0.92	0.10	0.92	0.10	-0.82
IV	Seeking Social Support	0.84	0.15	0.86	0.14	-2.07*
V	Escape Avoidance	0.93	0.16	0.91	0.11	1.59
VI	Problem Solving	0.79	0.11	0.81	0.08	-1.99*
VII	Reappraisal	0.92	0.13	0.96	0.12	-4.55***
VIII	Accepting Responsibility	0.45	0.07	0.40	0.06	6.17***
Total Coping Score		194.30	23.10	183.30	22.59	6.82***

*d.f.*= 106; \**p*<.05, \*\**p*<.01, \*\*\**p*<.001

Further analyses indicated gender differences in coping in relation to personality changes. Female carers sought more Social-support than male carers [ $t(105) = 2.88, p < .01$ ]. Carer's relationship with the patients also showed an association with their coping with personality changes. Nonspouse carers used more coping strategies (total coping) compared to spouse carers [ $t(101) = 2.45, p < .05$ ].

## DISCUSSION

The present study examined the ways carers cope with post-onset changes in patients with neurological disorders. Coping strategies used by carers are multidimensional, mainly being the emotion-focused strategies. Given that the majority of sample were predominately stroke patients with multiplicity of physical and behaviour problems, emotion-focused strategies which aim at distracting attention from the situation itself, seem to be the coping strategies of choice. It has been argued by Anderson (1977), and Terry (1991) that high levels of stress require an individual to use more emotion-focused coping to reduce tension.

Although more coping strategies were employed in relation to personality changes, Seeking Social-Support, and Cognitive Reappraisal were used significantly less by carers to cope with personality changes. One possible explanation for this finding is that a person may seek social support either for emotional reasons (emotion-focused) or may use it for informational purpose (problem-focused). In relation to physical changes, carer might have sought social support to collect information regarding handling such changes and the outcome of treatment. Carers also employed more cognitive reappraisal in relation to physical changes. In cognitive appraisal, an individual tries to create positive meanings out of the stressful situation. More use of this strategy in relation to physical changes could have helped carers to handle such problems in patients more effectively.

As expected, the context influenced the use of specific coping strategies. In relation to personality changes, more emotion-focused coping was employed, whereas with regard to physical changes more problem-focused coping was used. Thus, consistent with the hypothesis, carers used more emotion-focused and less problem-focused coping to handle personality changes than they did in the case of physical changes. The findings agree with Lazarus and Folkman's (1984) proposal that in highly stressful situations people tend to utilize more emotion-focused coping. Since personality changes were perceived as more stressful and threatening by carers, this might have increased the utility of emotion-focused coping among carers. Female carers sought

more social-support compared to their male counterparts. Males are expected to stay calm and to handle stressful situations by themselves, whereas, females on the other hand are more open to ask for help from others. Spouse carers are expected to provide care to their marriage partner and might have looked after them out of obligations, they used less coping strategies compared to nonspousal carers, who most probably would have found it difficult to provide care to the patient and had to use more coping strategies. However, the results from this study need to be interpreted with caution. The carers' reliance more on emotion-focused coping strategies could be for the reason that WOC predominately consists of emotion-focused strategies.

Further research is needed to examine the outcome of coping, i.e., to study the effectiveness of a particular type of coping in relation to the user's psychological adjustment. Such research may help design interventions for carers and they may be suggested to use those coping strategies which are effective to deal with a particular situation.

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