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Stress and coping in spouses of persons with spinal cord injuries

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Objective: To examine the sources of stress and the patterns of coping of spouses of persons with spinal cord injuries (SCI) among Hong Kong Chinese.
Design: A cross-sectional correlation design. A set of structured questionnaires and semi-structured interviews were administered.
Subjects: Forty spouses of persons with SCI were recruited and interviewed.
Outcome measures: These included coping strategies, depression, care-giving burden, life satisfaction and marital adjustment.
Results: The most stressful situations reported by the participants concerned health issues of their injured partners, the family and marital interactions, and the care-giving burden imposed on them. Cluster analysis indicated a potential at-risk group, characterized by high scores in external locus of control, inadequate coping modes and limited social support. They were noted to manifest high levels of depression, care-giving burden, low levels of life satisfaction and marital adjustment.
Conclusion: The identification of the potential at-risk group indicates that spouses of persons with SCI suffer levels of stress comparable to those of their injured partners. Rehabilitation plans should include this potential at-risk group to help them release the stress and to prevent them from developing clinically significant mental disorders.

Introduction

With recent medical advancements, there has been a significant reduction in the deaths of persons suffering spinal cord injuries (SCI) due to various kinds of complications. However, the residual deficits associated with SCI remain complex and variable. The increased survival rate and lifespan will make some problems even more important and extend beyond the individuals to their family members. The extent of disruption of family life and marital relationship resulting from the injury has not been fully studied from the perspective of patients' family members.[1–2] Across a variety of chronic disabilities, the accepted pattern of medical care now emphasizes reduced use of hospitalization, earlier discharge, and resumption of normal activities in order to avoid invalidism.[4,5] This trend thus increases the responsibility of both patients and their family members in coping with chronic conditions. How couples cope can be a crucial determinant of both

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biomedical and psychosocial outcomes for patients. In particular, the stress and care-giving burden encountered by the spouses of persons with SCI among the Hong Kong Chinese population has not been systematically examined.

Recent literature suggests that spouses of persons with SCI may suffer higher levels of stress than the other family members in taking up the care-giving role.[3,6] Three main factors are identified as strongly associated with adjustment outcomes. These are coping strategies,[7] locus of control,[8] and social support.[1,2] However, these are all Western-based studies. People from different cultures may have different sources of stress and corresponding coping patterns. Traditionally, Chinese are considered to be group-oriented, or more specifically, family-oriented and socially dependent people.[9] Role relationships described by the Five Cardinal Relations serve as a general guideline for being a proper person within a Chinese family. The Five Cardinal Relations are relationships between sovereign and subject, father and son, elder and younger brother, husband and wife, and friend and friend. Each party in the relationship is expected to perform their role according to the norms. Failure to achieve these role dualities will lead to discrimination by the others. The spouse of a person with SCI is obliged to perform this care-giving role in addition to their assumed spousal role in Chinese culture. However, Hong Kong has long been regarded as a melting point between the Eastern and Western cultures. Hong Kong Chinese may behave somewhat different from traditional Chinese. Moreover, Hong Kong is densely populated with about 6.5 million people. Such an overcrowded situation may have a particular effect upon stress and coping. Therefore, it is reasonable to hypothesize that the stress and care-giving burden faced by the spouses of persons with SCI in Hong Kong Chinese may be more intense than those of Western people on the bases of cultural and environmental factors.

As a preliminary study into the impact of SCI upon spousal adjustment in Chinese, this investigation aims to identify the types of stress and care-giving burden imposed on spouses of persons with SCI in Hong Kong. It also tries to identify any potentially at-risk cases among them in order to help them adjust better and prevent them from developing severe clinical symptoms of mental disorders.

Method

Participants

Purposive sampling of spouses of persons with SCI was drawn from regional hospitals, rehabilitation centres and other community sources including self-help groups and voluntary organizations in Hong Kong. In purposive sampling, judgement is used to include a sample with characteristics that are representative of the population of interest.[10] All of them met the criterion of their injured partners being at least two years post injury. This ensured that no participants were still in the initial phase of disruption and adjustment, and that they had experienced certain types of prolonged care-giving burden. Participants must have lived in Hong Kong for at least seven years to fit the criterion of being permanent residents in Hong Kong. A total of 94 persons with SCI were identified; only 66 of these were married. Among those couples, only 40 spouses agreed to take part in this study. The mean age was 41.2 (SD = 10.7). Thirty-five (87.5%) were female and five (12.5%) were male. Twenty-five (62.5%) were married before the injury. Fourteen (35%) of them were also physically disabled. Twenty-five (62.5%) were unemployed and took up a full-time caring role for their injured partners.

Measures

A set of measures on stress, and variables relating to the adjustment outcome was implemented to the participants. All the measures were translated to Cantonese. A two-stage back translation was adopted to ensure the original meanings of the measures. All the translated measures are reported as having impressive psychometric properties.

- *Levenson's Internality, Powerful Others, and Chance Scale* (LIPC)[11] was used to measure the locus of controls. The scale consists of three subscales: internality, powerful others, and chance. Separate subscale scores are obtained, with higher scores indicating higher

expectations of control by the source designated.

- *Provision of Social Relationship* (PSR)[12] was used to assess the participant's perception of social support. It comprises two subscales: family support and friend support. Two separate scores can be obtained with higher scores reflecting more social support perceived.
- *Ways of Coping Checklist* (WOC)[13] was used to measure the coping styles of the participants. The checklist describes a broad range of coping and behavioural strategies tackling emotion- and problem-focused aspects. The checklist consists of eight subscales: confrontive coping, distancing, self-control, seeking social support, accepting responsibility, escape-avoiding, planful problem solving and positive reappraisal. Scoring is based on yes–no response, i.e. 0 = does not use and/or not applicable; 1 = have used.
- *Beck Depression Inventory* (BDI)[14] was used to assess depressive status of participants. It consists of 21 statements exploring affective and somatic aspects of depression.
- *Satisfaction with Life Situation* (SWLS)[15] measured the participant's life satisfaction. Higher scores reflect more life satisfaction.
- *Katz's Adjustment Scale – Relative Forms 2 and 3* (KASR)[16] were used to measure performance of socially expected activities and relative's expectation of social role functioning respectively. A spousal rating on social role dissatisfaction score is obtained by subtracting form 2 from form 3.
- *Caregiver Burden Inventory* (CBI)[17] measured the care-giving burden imposed on the spouses. It consists of five subscales: time-dependence, developmental burden, physical burden, social burden, and emotional burden. The higher the scores of each subscale, the more severe the burden imposed on the spouses.
- *Dyadic Adjustment Scale* (DAS)[18] measured the marital quality and adjustment pattern of the participants. It consists of subscales of marital quality, namely dyadic satisfaction, dyadic cohesion, dyadic consensus, and affection expression. Total scores can be obtained by adding all the items together with higher scores indicating higher overall marital quality and adjustment.

Procedures

A cross-sectional design was adopted. A set of measures and semi-structured interviews were administered to participants. Consent was obtained from all the participants before the whole set of interviews and questionnaires were administered. An introductory interview was conducted by the investigator at the beginning of each session. Persons with SCI and their spouses were then interviewed separately. This study only reports the data concerning the stress and coping patterns of spouses of persons with SCI.

Data analysis

Cluster analysis[19] was used to identify and classify any naturally occurring coping patterns among the participants. It involved two cycles of analyses: (1) clustering the variables from coping strategies adopted (WOC), locus of control endorsed (LIPC), and social support perceived (PSR); and then (2) validating the cluster solution by another set of adjustment outcome measures, including BDI, SWLS, KASR, CBI and DAS. The cluster analysis was performed on the subscores of the WOC, LIPC and PSR in order to derive different coping subtypes within groups of spouses. In order to have a detailed analysis of the effect of clustering variables on care-giving burden and marital adjustment, the subscores of CBI and DAS were used instead of total scores in the data analysis. The investigator utilized the Proc Fastclus and Proc Cluster procedures of SAS for Windows, version 6.08. Proc Cluster was the program used to cluster variables with the hierarchical clustering procedure. Proc Cluster was used to validate the hierarchical solution with another nonhierarchical clustering procedure. Ward's method of minimum-variance clustering was used and squared Euclidean distance was used as the metric.

Results

Stress and coping strategies

The qualitative data volunteered by the participants on stress sources during the interview

are summarized in Table 1. The most stressful situations reported mainly concerned health issues to do with their injured partners, family and marital interactions, and the care-giving burden imposed on them. Work was also stressful for them because they had to undertake both the care-giver and employee roles at the same time. It was particularly stressful for those with full-time jobs. This might partly explain a higher percentage reporting strains in marital interaction and relationships than their disabled partners. Embarrassment caused by their disabled partners was seldom reported as having been a stressful situation in the past six months. None reported sex as a stressful situation. This may be due to the fact that Chinese tend to be conservative and unwilling to talk about sex openly.

The frequency of strategy usage in the stressful situations was recorded by the WOC. The most common strategies adopted by spouses in these situations are summarized in Table 2. The majority had adopted both the problem-focused and emotion-focused strategies when they had encountered stress in the past six months.

Table 1 Rank and order of stressful situations reported by spouse

Stressful situations	Rank	Percentage
Health- or disability-related affairs	1	50%
Family interaction and relationship	2	45%
Work	3	35%
Caring burden on family members	4.5	30%
Financial hardship	4.5	30%
Marital interaction and maintenance	6	15%
Living situation	7	7.5%
Embarrassment	8.5	2.5%
Others	8.5	2.5%
Sexual concern	10	0%

Coping patterns

A three cluster solution was derived (Table 3). Subjects in cluster 1 were labelled as 'externals with limited coping strategies and social support'. They had high scores on both external attributions, i.e. powerful others and chance control. They reported distancing and escape-avoidance as the two primary coping strategies. They also perceived less social support from friends than clusters 2 and 3 ($p < 0.05$).

Subjects in cluster 2 were labelled as 'internals with adequate coping strategies and social support'. They were characterized by high scores in internal locus of control, more problem-solving, positive reappraisal and more confrontive coping strategies. They also reported high social support perceived from family and friends.

Subjects in cluster 3 were labelled as 'multicontrols with mid-range coping strategies and adequate social support'. They showed equal levels of internal locus of control and chance control. They reported coping strategies in the mid-range between clusters 1 and 2, and tended to be more problem-focused. They also had high perceived social support from friends.

A multivariate analysis of variance indicated there was an overall significant effect between

Table 2 Top ranked strategies adopted by spouses

Strategy	Focus	Frequency	Percentage
1) I let my feelings out somehow	P	39	97.5%
2) I talked to someone about how I was feeling	E	31	77.50%
3) I tried to keep my feelings to myself	E	28	70.00%
4) I tried to keep my feelings from interfering with other things too much	E	28	70.00%
5) I went over in my mind what I would say or do	E	27	67.50%
6) I looked for the silver lining, so to speak, tried to look on the bright side of things	E	27	67.50%
7) I stood my ground and fought for what I wanted	P	26	65.00%
8) I came up with a couple of different solutions to the problem	P	26	65.00%
9) I did something which I didn't think would work, but at least I was doing something	P	25	62.50%
10) I asked a relative or friend I respected for advice	E	24	60.00%
11) I drew on my past experiences, I was in a similar position before	P	24	60.00%

Coping focus: P, problem-focused; E, emotion-focused.

Table 3 Cluster description along grouping variables in spouses

	Cluster 1 Externals (n = 11) Mean (SD)	Cluster 2 Internals (n = 12) Mean (SD)	Cluster 3 Multicontrol (n = 17) Mean (SD)	F-value	p-value
LIPC					
Internal control	23.18 (5.23)	31.00 (7.53)	34.82 (4.63)	13.57	0.0001 (i, ii)
Powerful others	30.73 (6.56)	18.42 (7.95)	20.53 (7.39)	9.34	0.0005 (i, ii)
Chance control	36.91 (4.61)	18.92 (5.20)	34.12 (4.30)	54.23	0.0001 (i, iii)
WOC					
Confrontive coping	2.82 (1.25)	3.75 (1.06)	3.65 (1.46)	1.84	0.1736
Distancing	11.80 (2.45)	15.00 (2.93)	11.47 (3.35)	5.42	0.0086 (i, iii)
Self-control	3.00 (2.14)	4.25 (1.36)	4.47 (1.87)	2.34	0.1101
Seek social support	3.55 (1.86)	3.92 (1.93)	3.24 (1.82)	0.47	0.6285
Accept responsibility	1.18 (1.25)	1.92 (1.62)	1.18 (1.42)	1.10	0.3438
Escape-avoidance	3.09 (2.02)	2.50 (1.78)	2.88 (2.18)	0.26	0.7753
Problem solving	2.36 (1.91)	4.50 (0.90)	3.47 (2.18)	3.98	0.0272 (i)
Positive reappraisal	0.82 (1.08)	4.17 (2.04)	3.24 (2.28)	9.06	0.0006 (i, ii)
PSR					
Family's support	18.64 (3.23)	21.75 (6.61)	22.65 (3.67)	2.57	0.0900
Friends' support	25.09 (5.66)	31.75 (6.61)	32.00 (3.66)	6.74	0.0032 (i, ii)

i $p < 0.05$ between cluster 1 and 2; ii $p < 0.05$ between cluster 1 and 3; iii $p < 0.05$ between cluster 2 and 3.
LIPC, Levenson's Internality, Powerful Others, and Chance Scale; WOC, Ways of Coping Checklist; PSR, Provision of Social Support.

the three clusters in terms of DAS, SWLS, BDI, K, R and CBI (Wilk's lambda = 0.2011, $F(30,44) = 1.8041$, $p = 0.0366$) (Table 4). Subscores on DAS and CBI gave a better understanding of the effect of the clustering variables upon them. Spouses in the 'externals with limited coping strategies and social support' group (cluster 1) were characterized by their higher levels of depression and care-giving burden (i.e. developmental burden, emotional burden and social burden) than the other clusters ($p < 0.05$). They showed lesser global dyadic adjustment scores, a lesser dyadic cohesion, and dyadic satisfaction than cluster 2 ($p < 0.05$). They were considered as the 'high risk' group. Moreover, spouses were distinguished to be older and having much longer period of marriage than those in clusters 2 and 3.

Spouses in the 'internals with adequate coping strategies and social support' group (cluster 2) were considered to be the 'well-adjusted' group. They were characterized by high scores in the global dyadic adjustment scale, dyadic cohesion and dyadic satisfaction, and satisfaction with life situation. They also scored low on care-giving burden, depression and social role dissatisfaction. However, scores on dyadic cohesion and satisfaction, depression, emotional and social care-giving burden did not differentiate them from those in cluster 3.

Spouses in the 'multi-controls with mid-range coping strategies and adequate social support' group (cluster 3) were characterized by their mid-range levels of various adjustment outcomes. Although they did not differ from those in cluster 2 with regard to the global dyadic adjustment scale, satisfaction with life situation, and care-giving burden, they showed significant higher scores on dyadic satisfaction, and lower scores on depression, and emotional care-giving burden than spouses in cluster 1. Moreover, they were younger and had shorter periods of marriage than those in cluster 1.

Discussion

Spouses in the cluster with external locus of control, limited coping strategies and limited social support could be considered to be a relatively 'high risk' group. They were characterized by

Table 4 Differences in outcomes between three clusters

	Cluster 1 Externals (n = 11) Mean (SD)	Cluster 2 Internals (n = 12) Mean (SD)	Cluster 3 Multicontrol (n = 17) Mean (SD)	F-value	p-value	
DAS						
Dyadic adjustment	95.91 (18.11)	116.83 (14.12)	106.35 (20.76)	3.99	0.0273	(i)
Dyadic consensus	47.45 (7.08)	52.25 (6.44)	47.65 (12.24)	1.21	0.3108	
Dyadic cohesion	9.18 (6.42)	16.92 (4.21)	13.88 (5.57)	5.08	0.0114	(i)
Dyadic satisfaction	31.55 (6.73)	39.25 (5.63)	37.35 (4.89)	6.10	0.0052	(i, ii)
Affection expression	7.73 (2.28)	8.42 (2.94)	7.47 (2.37)	0.52	0.5988	
SWLS	18.55 (6.76)	22.42 (6.11)	18.12 (5.66)	2.04	0.1445	
BDI	17.09 (9.30)	7.58 (5.88)	10.82 (7.40)	5.79	0.0066	(i, ii)
KASR	5.30 (2.95)	–0.08 (7.33)	1.82 (6.73)	2.58	0.1399	
CBI						
Development burden	10.45 (4.25)	5.58 (5.53)	10.53 (4.29)	5.06	0.0115	(i, iii)
Emotional burden	7.73 (5.16)	1.00 (2.00)	3.82 (2.81)	12.44	0.0001	(i, iii)
Physical burden	7.36 (2.80)	4.83 (4.97)	7.06 4.28)	1.37	0.2682	
Social burden	8.36 (5.05)	3.08 (4.03)	5.24 (3.13)	5.69	0.0071	(i)
Time burden	10.45 (6.33)	9.67 (5.52)	11.59 (4.89)	0.42	0.6590	
Current age	48.82 (13.16)	36.67 (4.81)	38.88 (9.07)	5.30	0.0096	(i, ii)
Duration of marriage	26.91 (16.34)	11.38 (6.71)	12.18 (5.93)	7.39	0.0020	(i, ii)

i $p < 0.05$ between cluster 1 and 2; ii $p < 0.05$ between cluster 1 and 3; iii $p < 0.05$ between cluster 2 and 3.
DAS, Dyadic Adjustment Scale; SWLS, Satisfaction with Life Situation; BDI, Beck Depression Inventory; KASR, Katz Adjustment Scale for Social Role Dissatisfaction; CBI, Caregiver Burden Inventory.

higher levels of depression and care-giving burden, and lower levels of satisfaction with life situation and marital adjustment than those in the other clusters.

Subjects in the other clusters, i.e. 'internals with adequate coping strategies and social support', and 'multi-controls with mid-range coping strategies and adequate social support', indicate that they seem to be relatively well-adjusted in terms of low levels of depression, care-giving burden, and high levels of life satisfaction and marital adjustment.

These findings are consistent with previous Western-based studies.[20,21] Bugaighis and colleagues[21] found that internal locus of control was correlated with higher levels of marital satisfaction. Menaghan[20] also found that marital partners using more optimistic and problem-focused strategies reported less distress and fewer marital problems than those using pessimistic and emotion-focused strategies. The current findings are also similar to those persons with SCI.[7,8] It indicates that there may be no significant difference in coping efforts between persons with SCI and their spouses. Therefore, spouses of SCI may also suffer from a coping problem similar to that of their injured partners if they have limited coping resources.

Clinical messages

- The study unfolds three clinically meaningful adjustment profiles of spouses of persons with spinal cord injury among Hong Kong Chinese. It alerts rehabilitation professionals to include the potential at-risk spouses in their treatment as early as possible.
- The coping patterns found in this study may guide us for future rehabilitation intervention, e.g. manipulate client's attributional belief, perceived social support and coping strategies endorsement may facilitate better adjustment.

Spouses of persons with SCI were found to encounter many stressful situations and underwent an adjustment process similar to that of their injured partners. Most of them used a variety of coping strategies, mainly emotion-focused strategies, to help them modulate such stress. In particular, care-giving burden was definitely reported as one main source of stress. However, rehabilitation professionals mainly limit their attention to persons with SCI, giving less attention to the patients' spouses. Such unequal and single-focus intervention may be inadequate. The findings from the study indicate that rehabilitation professionals should adopt a multifocused intervention strategy to ensure the best therapeutic results. The focus should extend to the adjustment problems faced by the spouses of persons with SCI, particularly the care-giving burden.

It may be that Chinese in particular experience additional stress in this situation because of the traditional role of female spouses in caring for their injured partners. Chinese are considered to be more conservative than their Western counterparts and are less willing to voice their internal world. Counselling services would be helpful in providing an open channel to alleviate the stress associated with injury and disability. By addressing the actual needs of the disabled partners as well as their spouses, couples may deal with their distorted perceptions and reopen communication about their own worries. Attention should also be paid to needs assessment and intervention approaches culturally relevant for Chinese persons with SCI and their spouses in the near future.

Finally, it should be noted that due to the difficulties experienced in obtaining a sampling frame for the population of persons with SCI in Hong Kong, the present study was undertaken with a nonrandom sample in a cross-sectional design. A major concern in the small sample size is its effect on the power of analysis and the generalizability of the results. The cross-sectional may further limit its causal inferences. However, it is compensated by a detailed analysis of the coping patterns among spouses of persons with SCI in Hong Kong. It is thought that since no comprehensive study on the impact of SCI upon spousal adjustment in Hong Kong has been conducted, it would be more worthwhile to start by having a broad-based understanding of this population before any largescale and longitudinal studies are planned and conducted.

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