ORIGINAL ARTICLE

Overprotection and the psychological states of cerebral palsy patients and their caretakers in Hong Kong: a preliminary report

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Objective To examine the relation between perceived overprotection and the psychological states of cerebral palsy patients and their primary caretakers in Hong Kong.

Design Cross-sectional survey, in which data of 14 pairs of cerebral palsy patients and their caretakers were analysed.

Setting Duchess of Kent Children's Hospital, Hong Kong.

Participants Cerebral palsy patients and their primary caretakers in Hong Kong.

Main outcome measures Perceived overprotection and psychological states.

Results Nearly two thirds of the 14 patients (mean age of 15 years) and 86% of the 14 primary caretakers (mean age of 47 years) perceived various levels of overprotection. For both patients and caretakers, perceived overprotection was positively associated with anxiety and unhappiness. The patients' and caretakers' psychological states and perception of overprotection were not related to the actual motor ability of the patients. Perceived overprotection of the patients was not related to that of the caretakers.

Conclusion Caretakers should be mindful that a well-meaning move may have undesirable consequences. More support and child-rearing education should be considered for caretakers.

Introduction

Cerebral palsy is the most common type of physical disability among children.[1] The non-progressive developmental disorder caused by brain lesion or defects early in life has a prevalence of 1.3 per 1000 children in Hong Kong.[2] Researchers have found both the cerebral palsy patients and their caretakers suffered more psychological problems than controls.[3,4] Besides, parents are often described as overprotective towards such disabled patients, and parental overprotection is reported to impact on their psychological well-being and independence.[5] For example, patients who perceived greater parental overprotection were more likely than their counterparts to be less happy, more anxious, and had a lower self-esteem.[5,6] As there is little relevant research on this topic in Hong Kong, this study set out to examine whether overprotection is related to the psychological well-being of local patients and caretakers. Based on overseas literature, we predicted that: (1) the patients' perceived overprotection would be positively related to their anxiety level, but negatively related to their happiness level, and (2) the caretakers' perceived overprotection would be positively correlated with their own anxiety level.

Key words
Caregivers; Cerebral palsy; Parent-child relations

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Methods

Procedures and participants

This study conducted between April and June 2007 was a joint project of the University of Hong Kong (HKU) and Duchess of Kent Children's Hospital (DKCH). The inclusion criteria were that the cerebral palsy patients must be at least 10 years old, have an IQ score of at least 70, and have no co-morbidity in terms of psychiatric disease, and that their caretakers must be the ones who assume the primary caretaking role.

Fifty-three of the DKCH patients who met the above criteria were invited by mail to take part in the study. Their primary caretakers were also invited. Potential patients and

caretakers were asked to come back to the hospital to participate in this study. Data collection consisted of two parts: (1) both the patients and the caretakers were required to complete a set of questionnaires; and (2) the caretakers were asked to participate in a focus group to talk about their experiences in the care of a cerebral palsy child. Only the questionnaire data are reported in this paper. Informed consent and debriefing procedures were followed. To ensure the patients had adequate mental ability to understand the questionnaires, they were required to undergo a short-form intelligence assessment. The Wechsler Adult Intelligence Scale-III[7] was administered to patients aged 16 years and above while a short form of the Hong Kong–Wechsler Intelligence Scale for Children[8] was administered to younger patients. The respective short forms of both tests comprised two verbal subtests (information and similarities).

Eighteen pairs of patients and caretakers, representing a response rate of 34%, participated in this study and completed the questionnaires. Among them, four were discarded due to incomplete data. Consequently, data from 14 pairs were used for the final analysis.

Ethics approval of the study was obtained from the Institutional Review Board of the HKU and Hospital Authority as well as the Departmental Research Ethics Committee of the Department of Psychology of HKU.

香港腦部癱瘓病人及其照顧者的過度保護和心理狀態：初步報告

目的 研究香港腦部癱瘓病人感受到的過度保護及他們的心理狀態與其照顧者的關係。

設計 將14對腦部癱瘓病人及其照顧者的數據作橫面調查。

安排 香港大口環根德公爵夫人兒童醫院。

參與者 香港腦部癱瘓病人及其照顧者。

主要結果測量 感受到的過度保護和心理狀態。

結果 在14對研究對象中，接近三分之二的病人（平均年齡為15歲）和86%的照顧者（平均年齡為47歲）感受到不同程度的過度保護。雙方所感受到的過度保護情況都與憂慮和不高興呈正相關，而他們的心理狀態和所感受到的過度保護與病人的實際活動能力無關。病人和照顧者感受到的過度保護，兩者之間亦沒有關係。

結論 照顧者應緊記他們一些善意之舉或會產生不良的後果。社會應考慮支持並向照顧者加強子女管教的教育。

Measures

The following issues were targeted for both patients and their caretakers, who completed the questionnaires.

Perceived overprotection

Perceived overprotection was assessed by a single-item scale adopted from a study on the self-esteem of cerebral palsy patients by Manuel et al.[9] The patients were asked about their perception of parent overprotection on a 4-point scale from "not at all overprotective" (1) to "very overprotective" (4). Similarly, the caretakers were asked to rate their level of overprotectiveness to the patient according to the same 4-point Likert scale.

Appraisal of severity of disability

Appraisal of severity of disability was measured by a single-item scale.[9] Patients were asked about their perception of the severity of their own disability, using a 4-point scale from "not at all disabled" (1) to "highly disabled" (4). Caretakers were asked about the severity of their patient's disability according to the same scale.

Hospital anxiety and depression

The Chinese Hospital Anxiety and Depression Scale[10] (CHADS) is a 14-item scale to measure anxiety and depression. Two scores (pertaining to anxiety and depression) can be obtained from this scale; higher scores indicate a higher level of anxiety and depression respectively. The Cronbach's reliability value of the CHADS_Anxiety subscale from the patients was 0.77 and that for the caretakers was 0.90. However the corresponding value of the CHADS_Depression subscale was -0.279 for the patients and 0.84 for the caretakers. The low and unacceptable reliability alpha of the depression subscale among the patients is inconsistent with other studies[9] and may be due to our small sample size. As a result, the CHADS_Depression scores of the patients were excluded from this report.

Satisfaction with life

The Chinese Satisfaction with Life Scale (CSWLS) developed by Shek[11] in 1998 was used to measure participants' overall satisfaction with life. A higher score means more satisfaction. The Cronbach's values of the CSWLS from the patients and the caretakers were 0.71 and 0.80 respectively.

Faces rating

The Faces Rating Scale (FRS), which has six facial expressions to represent different levels of happiness, was used to assess positive emotion of the participants. Both patients and their caretakers

TABLE 1. The psychological variables of the patients and caretakers (n=14 pairs)

Variable	Mean (SD)		*t*
	Patients	Caretakers	
Perceived overprotection	2.21 (1.12)	2.29 (0.83)	-0.211
Perceived disability severity	2.29 (0.99)	2.57 (0.94)	-1.00
Anxiety	7.71 (4.27)	9.79 (5.21)	-1.06
Depression*	-	6.77 (4.53)	-
Life satisfaction	22.15 (7.01)	20.62 (6.59)	0.531
Happiness	3.79 (1.25)	3.00 (1.30)	1.47
Perceived social support	64.93 (9.41)	56.71 (13.84)	1.66

* CHADS_Depression scores of patients were not reported because of low reliability of this subscale among the patients

were asked to choose a facial expression that corresponded most to their present happiness level. The FRS is a common scale to measure psychological states and pain level among young patients.[12] Higher scores imply higher levels of happiness.

In addition to the above inventories, patients' functional activities level were measured by the Melbourne Assessment of Unilateral Upper Limb Function[13] according to patient records obtained from the DKCH. The latter tool was found to have good construct validity.[13]

Statistical analysis

Descriptive statistics were provided first. Paired sample *t* tests were conducted to compare the scores of the patients and caretakers. Because of the small number of participants, non-parametric tests were also conducted and yielded entirely consistent findings, but only results from the parametric tests are reported in this paper. The anxiety, depression, and life satisfaction scores of the patients and caretakers were grouped according to their respective norms and Chi squared analysis was performed to assess whether there were any significant differences. Chi squared analysis was also conducted to compare the different levels of perceived overprotectiveness of the patients and caretakers. Pearson product moment correlations were then run to examine the relationship between the dependent and predicting variables.

Results

Participants

Patients

The 14 patients were comprised of five females and nine males, with ages ranging from 10 to 20 (mean, 15; standard deviation [SD], 3) years. All the patients' dominant upper limb had a higher functioning level (mean, 96%; SD, 6%) than that of the non-dominant side (mean, 78%; SD, 23%). The diagnostic subtypes of the patients were as follows: spastic-hemiplegia (n=3), spastic-diplegia (n=6), spastic-triplegia (n=3), dyskinetic cerebral palsy (n=1), and mixed (n=1). Four (29%) patients were studying in mainstream schools, while the other 10 (71%) were receiving education in special schools. Among the four patients studying in mainstream schools, three were secondary school students. Half (n=5) of the patients in special schools were receiving primary education. Five patients lived in the New Territories (Tseung Kwan O [n=2], Yuen Long, Tin Shui Wai, and Tsing Yi), another five lived on Hong Kong Island (Pokfulam, North Point, Shau Kei Wan, and Aberdeen), and the remaining four lived in Kowloon (Sham Shui Po, Lam Tin, Kwun Tong, and Wong Tai Sin).

Primary caretakers

Among the 14 primary caretakers, 12 were the biological mothers of their patients and the remaining two were a step-mother and an aunt. Their ages ranged from 33 to 55 (mean, 47; SD, 6) years. Half of them were housewives, five (36%) had a full-time job and the rest worked part-time. Half of the caretakers reported a monthly family income of less than $10 000, two between $10 000 and $20 000, and the rest more than $20 000.

Descriptive statistics

The mean and SD of all psychological variables are listed in Table 1. Paired sample *t* tests revealed no significant differences between the patients and the caretakers in terms of psychological states.

Perceived overprotection

Nearly two thirds (n=9) of the patients perceived different levels of overprotection, including three who perceived being very overprotected. On the other hand, 12 of the caretakers regarded themselves as overprotective, though seven of them thought they were only slightly overprotective. Chi squared analysis showed no significant difference between the two groups, χ^2 (9, n=14)=10.85, P=0.286 (Table 2).

Anxiety and depression

Based on the norm of the Hospital Anxiety and Depression Scale (HADS),[14] seven of the children showed a normal anxiety level. However, four patients had scores indicating a probable anxiety disorder. For the caretakers, five had a HADS anxiety score greater than 10, consistent with the anxiety disorder. On depression, five had a depression score above the threshold, indicating probable depressive disorder. Chi squared analysis showed there was no significant difference between the patients' and caretakers' anxiety levels, χ^2 (4, n=14)=0.629, P=0.179 (Table 3).

Satisfaction with life

On life satisfaction, four (31%) of the patients and four (31%) of the caretakers reported various levels of dissatisfaction. The remaining patients and caretakers scored at least 20 on the satisfaction with life scale, which was the threshold used to differentiate between satisfaction and dissatisfaction.[15] The corresponding Chi squared analysis showed no significant difference between the patients and caretakers, χ^2 (4, n=13)=6.67, P=0.154 (Table 4).

Correlations

Finally, the Pearson product moment correlations were conducted for the patients and caretaker groups separately (Table 5).

Patient-perceived overprotection correlated positively with their own anxiety (r=0.680, P<0.01) and negatively with their happiness level (r= –0.536, P<0.05). Thus, cerebral palsy children who perceived greater levels of overprotection tended to be more anxious and less happy.

Caretakers who perceived a greater tendency to overprotect their cerebral palsy child tended to exhibit more depression and anxiety responses (depression: r=0.676, P<0.01; anxiety: r=0.731, P<0.01). Nevertheless, their happiness level did not correlate with their overprotection score (r= –0.401, not significant). Instead, caretakers' satisfaction level correlated negatively with their perception of their patients' disability (r= –0.579, P<0.05).

The patients' upper limb functioning levels did not correlate with any of their own or caretakers' psychological variables. Both the patients' and caretakers' perceived overprotection had no relationship to their respective views on the severity of the patient's disability. Nor did the perceptions of the patients and caretakers correlate.

TABLE 2. Perceived overprotection of the children by their caretakers*

Overprotectiveness level†		Caretakers				Total
		One	Two	Three	Four	
Patients	One	1	1	3	0	**5**
	Two	1	3	0	0	**4**
	Three	0	2	0	0	**2**
	Four	0	1	1	1	**3**
Total		**2**	**7**	**4**	**1**	**14**

* χ^2=10.85, df=9, n=14 patient-caretaker pairs, P=0.286. Because of our small sample size, Wilcoxon sign ranks test was performed to examine if there was a significant difference on perceived overprotectiveness between patients and their caretakers. The result was not significant (z= –0.364, P=0.715) which was consistent with the Chi squared test result

† Level one=not at all overprotective; level two=slightly overprotective; level three=quite overprotective; level four=very overprotective

TABLE 3. Anxiety levels of the patients and their caretakers*

Anxiety level†		Caretakers			Total
		One	Two	Three	
Patients	One	3	0	4	**7**
	Two	2	1	0	**3**
	Three	3	0	1	**4**
Total		**8**	**1**	**5**	**14**

* χ^2=0.629, df=4, n=14 patient-caretaker pairs, P=0.179

† Level one=normal level (0-7); level two=suggestive presence of anxiety disorder (8-10); level three=probable presence of anxiety disorder (≥11). The three levels were classified according to the established norms[14]

TABLE 4. Life satisfaction levels of patients and their caretakers*

Life satisfaction level†		Caretakers			Total
		Satisfied	Neutral	Dissatisfied	
Patients	Satisfied	4	0	3	**7**
	Neutral	1	1	0	**2**
	Dissatisfied	3	0	1	**4**
Total		**8**	**1**	**4**	**13**

* χ^2=6.67, df=4, n=13 patient-caretaker pairs, P=0.154

† Satisfied=a score of 21-35; neutral=20; dissatisfied=5-19. The satisfaction levels were classified according to the established norms[15]

Discussion

Patients' perceived overprotection

The objective of this study was to examine the relation between perceived overprotection and the psychological states of the cerebral palsy patients and caretakers in Hong Kong. The analysis shows that patients' perceived overprotection correlates with their levels of anxiety and happiness, which is consistent with prior research.[5,6] It should also be noted that the percentage of our patients sample with probable psychopathology was higher than reported elsewhere. For instance, four of the patients had probable anxiety disorder and also four were not happy with their life. Besides, nearly two thirds of the patients (n=9, 64%) perceived various level of overprotection. This percentage is higher than figures reported in the literature.[3,5] Nevertheless, our small sample size does not allow a definite conclusion, as the discrepancy may be a result of the differences in measurement parameters and the numbers of subjects. For example, Anderson and Clarke[3] measured overprotectiveness with specific questions like whether excessive help was perceived and whether independence was encouraged. Their study also had a larger sample size (86 cerebral palsy patients and 30 spina bifida patients).

The correlation analysis also reveals that the patients' perception of overprotection is not related to the caretakers' views, implying that whatever the caretakers think about their level of protection, the patients may not necessarily agree. It is thus important

TABLE 5. Correlations between various psychological and demographic variables*

Variable†	(1) Anxiety	(2) Depression	(3) SWL	(4) Happiness	(5) Over-protection	(6) Disability	(7) Dom limb	(8) Non-dom limb
(1) Anxiety	-	-	-0.413	-0.632‡	0.680§	-0.179	-0.211	-0.454
(2) Depression	0.922§	-	-	-	-	-	-	-
(3) SWL	-0.620‡	0.617‡	-	0.509	-0.420	0.224	0.337	0.392
(4) Happiness	-0.636‡	-0.697§	0.836§	-	-0.536‡	0.424	-0.309	-0.033
(5) Overprotection	0.731§	0.676§	-0.401	-0.358	-	-0.121	0.005	-0.134
(6) Disability	-0.115	-0.089	-0.579‡	-0.189	-0.028	-	-0.103	0.051
(7) Dom limb	-0.007	0.198	0.058	-0.327	-0.228	-0.399	-	-
(8) Non-dom limb	0.144	0.287	-0.007	-0.319	-0.155	-0.284	-	-

* Patients' results are presented in grey shading; other data are caretakers' results; n=14 patient-caretaker pairs. CHADS_Depression Scale results among the children were not reported because of low Cronbach's reliability alpha

† (1) Anxiety=CHADS_Anxiety Subscale; (2) Depression=CHADS_Depression Subscale; (3) SWL=Satisfaction with Life Scale; (4) Happiness=Faces Rating Scale; (5) Overprotection=Perceived caretakers' overprotection; (6) Disability=Perceived severity of patients' disability; (7) Dom limb=Dominant upper limb's functioning level; (8) Non-dom limb=Non-dominant upper limb functioning level

‡ P<0.05

§ P<0.01

for the caretakers to understand the impact of their child-rearing practices. A well-meaning move may be perceived differently and bring unintended and undesirable consequences.

Caretakers' perceived overprotection

Our findings show that caretakers' perceived overprotection correlates positively with their anxiety and depression levels; those who perceive greater overprotection of their patients are more anxious and depressed. Past research on the relation between overprotection and the psychological state of caretakers of disabled children is meagre, but our findings corroborate the link between general parental overprotection and parental anxiety.[16] While the linkage may not be specific to parents with disabled children, the suggestion that overprotection was the parents' response to their internal anxiety sheds light on the possible nature of the relationship between the two variables. In particular, overprotection may be just a product of caretaker anxiety or could be the cause. Other researchers too[6,17] noted that parents with disabled children tended to be guilt-ridden and that they commonly do everything to compensate for their patients' disability.

This correlation is also important because 86% (n=12) of them admitted they were overprotective, although most (n=7) considered their protection was only slightly excessive; the percentage being higher than the 25% reported in the literature.[3] However, the differences in the questions asked and sample size between the present and prior studies should be borne in mind. By contrast, more than a third (n=5, 36%) of the caretakers in our study had anxiety and depression scores indicating probable mood disorder; the percentage being slightly more than that described in the literature (30% of mothers with depressive symptoms).[18]

Impact of patients' functional level

The functional level of the patients had a limited impact compared to perceived overprotectiveness. In the case of the patients, the lack of a correlation between motor ability and psychological states (like anxiety and happiness) is not surprising, as the reported relationship in the literature is unclear.[3] Resnick[6] summarised the possible reason why individuals born with disability might be less affected by physical disability than the psychological state or mindset that is shaped by the condition and the social reaction to it.

Contrarily, the lack of a relationship between the patients' perceived overprotectiveness and motor ability in our study seems to contradict prior reports of positive[3] and negative[6] correlations. However, a negative as well as a lack of correlation have similar implications—the severity of disability cannot fully explain the relationship between overprotectiveness and negative psychological outcomes.

For the caretakers, the correlation analysis also shows that their psychological state is not related to the patients' motor ability, which is consistent with the literature.[18,19] However, caretakers who perceived greater patient disability enjoy less life satisfaction. The implication is that perception plays a bigger role in the psychological state of the caretakers than the patient's objective functional level.

That there being no relation between the caretakers' perceived overprotection and the actual functional ability of our patients, was inconsistent with the study of Anderson and Clarke.[3] The latter report found that mothers with more severely disabled children saw themselves as more overprotective. As

discussed earlier, differences in study design may explain the discrepancy in results.

Limitations and recommendations on future studies

The major limitation of our study was the small number of subjects. With only 14 patient-and-caretaker pairs, generalisation may be difficult. Being mainly a correlation analysis, the nature of the relationship between overprotection and psychological states cannot be fully explained. However, the study does provide an outline of psychological issues pertinent to local cerebral palsy patients and their caretakers. More research is needed to draw a fuller picture of the overprotection problem, including the causal relationship between caretakers' overprotective behaviour and their psychological states, as well as the manifestations of overprotection perceived by the patients and caretakers.

Conclusion

This study provides supporting evidence that in Hong Kong perceived overprotection correlates with some of the psychological states of the patients and their caretakers. Caretakers should become more educated about the impact of their child-rearing practices, as a protective act may be interpreted as excessive by the patients and could cause psychological distress.

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