

·Special Paper·

A Post-Discharge Service for Brain Injury Patients in Hong Kong

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Abstract

Objective: To establish an affordable and easily accessible post-discharge telephone follow-up service for people with brain injuries and their caregivers, and thus to provide an evidence base for developing cost-effective continuous care, region-wide.

Method: Thirty-five adult patients with brain injuries and 26 caregivers were recruited from Neurosurgical Unit at Queen Mary Hospital in this study. Participants were administered a structured telephone interview at the fourth week post-discharge, and again at the twelfth week post-discharge. Patients and caregivers at risk of poor adjustment were referred for further medical consultation or psychological intervention. Patients' physical and cognitive functioning were investigated while both patients and caregivers' emotional functioning and perceived social support were explored. Satisfaction of the current service provided was also examined.

Result: Majority of patients reported significant improvement in physical condition. A sizable number of patients experienced cognitive difficulties and reported insufficient psychosocial support received following discharge from hospital. Majority of caregivers reported compromising health, emotional and social functioning in caregiving. Both patients and caregivers reported satisfaction with the service with caregivers reported higher satisfaction.

Conclusion: Findings from current study showed that both patients of brain injuries and caregivers benefited from the post-discharge telephone follow-up service. Both of them agreed that such service helped to identify people at risk of poor adjustment, provide timely advice and emotional support. Our findings also indicated that caregiving significantly impairs caregivers' physical, emotional, and social functioning, suggesting a need to offer them advice on care skills, role or living adjustments, and stress management.

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Key word brain injury; cognitive functioning; post-discharge service; carer stress

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摘要

目的: 建立针对脑损伤患者及其看护者的可负担、易获取的出院后电话跟进服务, 并为发展区域内有成本效益的连续监护体制提供实证基础。

方法: 本研究从香港大学玛丽医院脑外科招募35名成年脑损伤患者和26名看护者。参与者在出院后第4周和第12周各接受一次结构化的电话访谈。有调整能力不足风险的患者与看护者将被送交进一步的医疗咨询或心理干预。患者的生理和认知功能, 以及患者与看护者的情感功能、知觉到的社会支持和对当前所提供的服务的满意程度都被列入调查。

结果: 大部分患者报告他们的生理状况有明显改善。相当多的患者在出院后经历过认知困难并报告所接受到的社会心理支持不足。大多数看护者报告在看护期间健康、情感功能和社会生活受损。患者与看护者都对服务表示满

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1098 www.rehabi.com.cn

意,看护者的满意程度更高。

结论:脑损伤患者及其看护者都受益于出院后电话跟进服务。两者都同意该项服务有助于识别有调整能力不足风险的个体,并提供及时的建议和情感支持。看护工作会明显损害看护者的生理、情感功能和社会生活,提示需要为他们提供关于看护技巧、生活调整和压力管理的意见与建议。

关键词 脑损伤;认知功能;出院后跟进服务;看护者压力

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Patients with brain injuries experience considerable challenges upon discharge from hospital. Cognitive impairment and mood disturbance are the two major challenges determining the long-term adjustment outcomes among these patients^[1-6]. These two challenges may also impact the psychological well-being of caregivers, both directly and indirectly: insufficient knowledge of the medical condition they are dealing with, and the load of work associated with the provision of care for the patients, makes the process distressing for caregivers^[7-9].

Professional surveillance can help patients adjust to daily life during the post-discharge period, while education and skills training helps caregivers cope with the burden of round-the-clock care and supervision^[10-13]. A pilot study conducted by the Laboratory of Neuropsychology (Lab), established by The University of Hong Kong, offers evidence suggesting the benefits of continuous intervention, using a sample of Hong Kong Chinese individuals with acquired brain injuries, and their caregivers. Our survey indicated that most of the patients and caregivers (90%) demonstrated a need for regular updates on their cognitive and psychological functioning. However, consistent with previous evidence from studies conducted in the West^[14-16], accessibility and transportation were the biggest barriers to attending regular out-patient check-ups.

1 The present project

The Lab, in collaboration with outpatient clinics at Queen Mary Hospital and Tung Wah Hospital in Hong Kong, designed a post-discharge telephone follow-up service for patients with brain injuries and their caregivers. The objective of this project is to establish an affordable and easily accessible post-discharge telephone follow-up service for people with brain injuries and their caregivers, and thus to provide an evidence base for developing cost-effective continuous care, region-wide. The specific aims of the telephone service were: ①To identify and refer patients and caregivers at risk of poor adjustment to spe-

cialist medical and psychosocial services; ②To provide education and advice to both patients and their caregivers for adjustment and social re-integration after discharge; ③To establish a health profile for discharged brain injury patients.

2 Method

2.1 Participants

The demographic characteristics of the participants are summarized in Table 1. The patients ranged in age from 18 to 84 years, and, in terms of gender composition, 21 were female and 14 were male. Of these participants, four (11%) reported having received no formal or primary education, while 19 (54%) had completed secondary education, and four (11%) had completed at least tertiary education. The remaining eight participants (23%) did not report their educational background. The average time since discharge was 31 days. The 26 caregivers ranged in age from 18 to 65 years. Of the caregivers, 15 (58%) had completed secondary education, eight (30%) had completed at least tertiary education, and three (12%) did not report their education.

2.2 Procedure

Upon obtaining Ethics Committee approval from The University of Hong Kong and the Hong Kong Hospital Authority, recruitment was conducted in the Neurosurgical Unit at Queen Mary Hospital (QMH) between September 2006 and December 2008 (Figure 1). After being fully apprised of the study, 35 patients and 26 caregivers gave their written consent to participate and were administered a structured telephone interview at the fourth week post-discharge, and again at the twelfth week post-discharge. The interviews were conducted by a professional team consisting of nurses, a clinical psychologist, and a research assistant. Based on the first interview, patients and caregivers at risk of poor adjustment were referred for further medical consultation or psychological intervention. This post-discharge service is both accessible and affordable, and so is conve-

nient for patients who experience difficulty in traveling and caregivers who are not able to take time off from work.

2.3 Measure

For the patients, the telephone interview assessed physical, cognitive, and emotional functioning, and also perceived social support, whereas the interview for caregivers included an assessment of psychological functioning and a consultation on the provision of care. At the second interview, both groups were also administered a questionnaire assessing their satisfaction with the service.

3 Results

3.1 Patients' health status

3.1.1 Physical functioning: The results showed that many patients were able to maintain daily functioning such as personal hygiene, household chores, and social activities after discharge (Table 2). However, a portion of patients reported impairment in physical functioning. Between 20% and 30% of patients reported dizziness, tinnitus, polyuria, constipation, slow responses, poor appetite, lower back

Table 2 Patients' overall health status rating at the first and second interviews

	Better		The same		Worse		Not applicable		Missing	
	n	%	n	%	n	%	n	%	n	%
T1	229	26.17	366	41.83	23	2.63	155	17.71	102	11.66
T2	129	17.79	463	63.86	11	1.52	120	16.55	2	0.28

pain, and lower limb weakness, more than half reported mild and occasional fatigue. Nearly half of the patients experienced headaches and blurred vision. About 40% of the patients experienced frequent dryness of mouth. Between 30% and 40% complained of memory problems and insomnia. Nearly 30% of the patients indicated that they experienced some difficulty reading newspapers and watching television because of poor concentration and low energy levels, more than 20% also reported some difficulties in performing exercises and engaging in hobbies due to low energy levels.

3.1.2 Cognitive functioning: The scores on the screening test of cognitive functioning indicate that most patients were experiencing some difficulties at the first interview, and about 30% of patients still experienced some degrees of cognitive deficits at the second interview (Table 3). All patients were fully oriented to time, place, and person, apart from a small number who failed to provide accurate personal information. About 60% to 90% of the patients reported intact attention, working memory, mental flexibility, and cognitive fluency. About 20% of the patients showed signs of memory problems.

3.1.3 Emotional functioning: Our results showed that more than 90% of the patients reported no particular emotional disturbance at the first post-discharge interview. At the second interview, less than 5% of them experienced some degree of stress and depression (Table 3).

3.1.4 Perceived social support: The majority of the patients reported having mutual trust, support, and acceptance from family members and friends. Some patients, however, reported having the following difficulties: about 20% were unable to share their inner thoughts and feelings, especially regarding sadness, with family members, about 25% perceived that family members avoided talking about their own fears and worries, nearly 20% reported having a lot of blaming among family members, about 25% found it difficult to have mutual agreement on decision making with family members, about 20% stated that they never accept-

Table 1 Demographic characteristics of participants

	Patient		Caregiver	
	1st Follow-up	2nd Follow-up	1st Follow-up	2nd Follow-up
N	35	29	26	19
Sex				
Female	21	17	15	11
Male	14	12	10	8
Missing	0	0	1	0
Age	18-84	18-84	18-65	18-65
Education level				
Primary or below	4	2	0	0
Secondary	19	18	15	11
Tertiary or above	4	3	8	6
Missing	8	6	3	2
Mean days since discharge	31	102	33	98

Figure 1 Recruitment procedure for participants

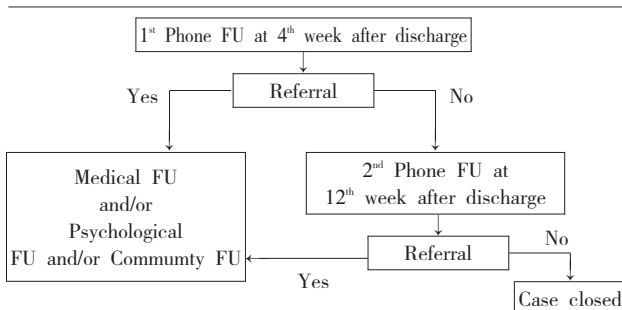


Table 3 Patients' report of difficulties in individual aspects of functioning

	Physical		Cognitive		Emotional		Economic		Confidence		Self-care	
	n	%	n	%	n	%	n	%	n	%	n	%
T1	28	41.79	25	37.31	1	1.49	1	1.49	11	16.42	1	1.49
T2	13	54.17	7	29.17	4	16.67	0	0	0	0	0	0

ed assistance or rarely sought help from others, and nearly 40% did not join activities organized by community or self-help groups.

3.2 Caregivers' health status

3.2.1 Emotional functioning: Over 90% of the caregivers reflected that by taking care of the patient, they felt close to the patient. Nearly 90% of the caregivers stated the belief that they had tried their best to look after the patient, had withstood hardship together with the patient. The majority of the caregivers (about 80%) enjoyed being with the patients. Nearly 80% of the caregivers felt that their effort was appreciated by patients. However, the negative impact of caregiving was also reported. Between 15% and 35% of the caregivers felt that they had lost control over their own lives. About 20% reported that they felt exhausted and about 17% indicated that their health was compromised. In general, the caregivers perceived an increase in the negative impact of caregiving on their health and social lives between the first and the second interviews. About 15% of the caregivers believed that they were unable to identify the patients' needs and half of the caregivers reported that they seemed to be the only caregiver to patients. About 10% of the caregivers reported an anxious and depressive mood and regarded caregiving as stressful. The caregivers' ratings on emotional distress resulting from the provision of care are summarized in Table 4.

3.2.2 Perceived social support: The caregivers did perceive mutual acceptance, trust, and support among family members in the face of adversity. They also reported good quality of relationships with other family members and, in

general, good social networks and support. However, some difficulties remained. Between 20% and 30% of the caregivers reported difficulty sharing their thoughts and feelings, especially sadness, with other family members. Nearly 40% of the caregivers avoided talking about their own fears and worries and about 20% had never sought help from others in coping with adversity. Around 90% of the caregivers had never or seldom participated in community activities or self-help groups. Nearly 20% reported having a lot of blaming among family members. About 30% indicated that mutual agreement on decision making was difficult among family members.

3.3 Patients' and caregivers' satisfaction with the service

In general, both patients and caregivers evaluated the present project positively. Nearly all patients (80%) and caregivers (100%) agreed that the telephone follow-up service provided a regular channel for healthcare professionals to monitor the physical health and cognitive and emotional well-being of patients. Nearly all patients (80%) and caregivers (100%) agreed that healthcare professionals were able, through the telephone service, to identify and refer those patients at risk of poor adjustment for specialist follow-up. In addition, the patients and caregivers did not have to wait for their next medical appointment in order to have their queries addressed. Nearly all patients (80%) and caregivers (90%) appreciated the emotional support and professional advice received through the telephone service. Nearly all patients (80%) and caregivers (90%) agreed that the telephone service saved their transportation costs and time. Overall, 83% and 100% of the patients and caregivers respectively were satisfied with the telephone follow-up service. About 70% of the patients and caregivers welcomed the implementation of the telephone follow-up service. The caregivers reported higher satisfaction with the service than the patients, suggesting a greater demand for the service among the caregivers.

Table 4 Caregivers' ratings on emotional distress associated with caregiving

Total	Stress Score		Anxiety Score		Depression Score		
	>or=21		>or=14		>or=14		
	n	%	n	%	n	%	
T1	26	2	7.6	1	3.8	2	7.6
T2	19	1	5.3	2	10.5	0	0

0=Did not apply to me at all,1=Some degree or some of the time, 2=Considerable degree or a good part of the time, 3=Very much or most of the time.

4 Discussion

This project provides an evidence base on the adjustment to daily life of patients with brain injuries and their caregivers, and their satisfaction with a post-discharge telephone follow-up service. The data help guide the development of population-based rehabilitation programs for such patients^[17-19]. Nearly all patients reported

fair or significant improvement in their physical condition between the first and the second interviews, and less than 2% of them reported deterioration, most patients also perceived significant improvement in their mood at the second interview, suggesting a gradual adjustment to their brain injury. Our results suggest, however, that a sizable number of patients with brain injuries experience cognitive difficulties and perceive that the psychosocial support received following discharge from hospital is insufficient. In particular, difficulty in gaining social support and an ineffective coping style are not uncommon responses among the present sample, possibly due to an interaction between family adaptation to and individuals' coping with the consequences of brain injuries^[20-21]. In summary, the development of services to enhance patients' cognitive rehabilitation, family relationships, and also for the improvement of physical functioning, is necessary^[22-25].

A number of caregivers experienced stress due to the provision of care to patients and the adjustments they had to make in order to get along with patients, they also reported impairments to their health and social life. Also, despite having family and social support, a sizable proportion of the caregivers reported tension among family members, and a number of them did not share their distress with family members or seek help from others in coping, which is consistent with previous evidence in Caucasian populations^[26]. To optimize psychosocial rehabilitation outcomes among patients with brain injuries, the well-being of caregivers should be enhanced^[27-28]. This could be achieved by educating caregivers on the relevant medical conditions but also teaching stress management and strategies for coping with demanding caregiving situations^[29-35].

In general, all participants, particularly the caregivers, were highly satisfied with the telephone follow-up service discussed here. Nearly all patients and caregivers agreed that a regular telephone follow-up service can identify people at risk of poor adjustment, provide timely advice and emotional support, and address some of their queries without the need to wait for the next medical appointment^[31]. Our findings indicate that caregiving significantly impairs caregivers' physical, emotional, and social functioning, suggesting a need to offer them advice on care skills, role or living adjustments, and stress management.

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