Family at the Bedside: Strength of the Chinese Family or Weakness of Hospital Care?

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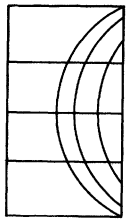

CULTURE AND MEDICINE

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Introduction

Hospital care is a distinctly modern phenomenon. With increasing division of labour in society, ever more responsibilities of meeting basic human needs are delegated by the family to other institutions. Although the family remains a vital component of modern health care throughout the world, health care responsibilities have largely shifted to a different social institution – the formal organization of the hospital. In the hospital, medical care is constructed and practised in accordance with technical and bureaucratic principles. The transfer of health care from the family to a formal institution has profoundly changed the organization of medical care in the West (Rosenberg, 1987).

Interestingly, the literature continues to recognize that family involvement is helpful for a patient's recovery process as it reduces a patient's stress from being cared for by strangers. Despite the importance of the family in the recovery of the patient, modern western health care delivery, often by design, limits the involvement of a patient's family. Visiting policies, for instance, help separate the patient and his or her family. The central assumption is that the hospital is responsible for the complete care of its resident patients.

Although Taiwanese medical care has largely emulated the model of

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western medical organization in many respects (L.-Y. Chang, 1993, 1998a, 1999), a peculiar feature of the Taiwanese system is that the family members of a patient are often the *main* caregivers during the patient's hospitalization. The nursing staff only play a minor technical role that directly helps the physicians in delivering medical treatments rather than complements the medical treatment process by attending to the less technical needs of patients. Family involvement in providing care and services is conspicuous and ubiquitous in Taiwanese hospitals. The family members of patients are allowed to stay in their wards for as long as they wish every day. Family members often have a better knowledge of patients' diagnoses, treatments and prognoses than do patients themselves. However, neither patients nor their family members participate in most of the medical decisions (L.-Y. Chang, 1993). Although it is known that family members are the main caregivers for patients during hospitalization in mainland China (Schneider, 1993), the basis and theoretical implications of this phenomenon have not yet been examined.

Why is there such intensive and extensive family care in Taiwanese hospitals? The question is worth studying for four reasons. First, it fills a gap in the research into the interface of the family and the hospital – the juxtaposition of a highly personal institution and a formal/impersonal organization under critical situations of life and death. In recognizing the importance of the family in caring for the ill, most studies in the literature only study long-term care at home. Past studies emphasize the stress and strain on the family, the forms of caregiving and the availability of a social support network. This literature shows that family involvement in patient care not only affects the work and daily routines of family members, but also generates tension among family members regarding who does what. Nonetheless, family caregiving inside the hospital seldom appears as a research topic in western societies. Nor has this been done in Taiwan. This articles fills this gap by closely examining the reasons for the intensive and extensive family involvement in hospital care.

Second, it is socially relevant. Hospital care is a major component of national expenditure and affects the well-being of virtually everybody and often several times over the family life cycle. In 1999, health expenditure in Taiwan amounted to 5.8 percent of the gross domestic product (GDP), a rise from 3.3 percent in 1980 (Ministry of Health, 2000). The Taiwan Commission on Economic Development (1990) recommended that public spending on health be raised so that total health expenditure reached 7 percent of GDP. The rationale for this proposal is that increased spending will improve the quality and distribution of health care. But will increased spending on health care really lead to significantly higher quality and a more even distribution of care? Is 5.8 percent of the GDP on health care too low to provide decent care to the general public?

Third, it undermines the validity of conventional estimates of health care

expenditure in modern societies and Taiwan in particular. It is noteworthy that 57 percent of the health expenditure is borne by the public privately according to governmental statistics. Hospital care is usually considered a direct cost of illness (Phelps, 1992). However, conventional cost estimates of hospital care routinely overlook the substantial social and monetary costs borne by patients' families. Studying family involvement in hospital care will enhance our understanding of the cost transfer from the hospital to the family, and the potentially serious underestimation of real health care expenditure.

Finally, it offers a unique opportunity to look into the cultural logic of Chinese family resource mobilization. Bedside care usually demands only a temporary interruption from daily routines. The mobilization of support can easily go beyond the family circle. Therefore, the extent and format of family participation in bedside care are suggestive of the interpersonal relationships of the family and the commitment of the members to each other. The arrangement of bedside care within the hospital can be dictated by the capability of the family to mobilize resources in coping with a short-term need. Not surprisingly, Chinese family devotion to caring for the ill is commonly thought to exemplify the strength of the Chinese family system. The extent to which the devotion is driven by moral obligation is the focus of the empirical analysis in this article.

There are two leading hypotheses for this intriguing phenomenon: the strength of the Chinese family and the weakness of Taiwanese hospital care (L.-Y. Chang, 1993, 1998b). Does family involvement reflect the value system of a culture, or is it a pragmatic coping strategy in face of inadequate care provided and organized by Taiwanese hospitals? This article studies the meaning of family involvement in hospital care and illustrates how moral reasoning is shaped by structural constraints and how individuals develop coping strategies when confronted with a conflicting situation. To this end, I address two preliminary questions: (1) What do families do in hospitals? (2) How does a patient's family decide on the organization of bedside care in the hospital? What are the conditions that determine the arrangement of family bedside care?

The results show that family involvement in hospital care is less a manifestation of moral obligation and more of an adaptive or reactive behaviour towards the organization of hospital care. By restricting its service to narrowly defined medical treatments (medication, surgery, diagnostic testing and so on), the hospital thereby leaves most of the burden of patient care to a patient's family. With the well-being of a family member at stake, the family has little choice but to be deeply involved in the care of its member in the hospital. Following the section on data and methods, in the third section, I closely explore life in hospital as a patient and what family members do there. The fourth section focuses on how the bedside care is organized. The fifth

section examines the two competing hypotheses, the strength of the family or the weakness of the hospital, in explaining the intensive and extensive involvement of the family in inpatient care. The conclusion is provided in the last section.

Data and Methods

The data used in this article were collected in Taiwan during 1990 and 1991. Three hospitals agreed to participate in this research: a teaching hospital, an area hospital and a regional hospital. The teaching hospital is located in Taipei, the capital city of Taiwan. The area hospital, one of the second-tier hospitals, is situated in the city of Hsin-chu. The regional hospital, a third-tier one, is located in a rural area called I-lan.

Four criteria were used to select the patients for this study: (1) they had been hospitalized for a given diagnosis for the first time; (2) the symptoms prompting the request for medical care occurred within six months prior to hospitalization; (3) the patients' primary diagnoses were illness of the cardiovascular system (CVS), diabetes (DM), chronic obstructive pulmonary disease (COPD), cancer, or myocardial infarction (MI); and (4) the illness has reached a life-threatening stage and required immediate medical treatment. During four months of fieldwork in the three hospitals, I collected complete data on 70 patients. Among these patients, 25 had suffered a CVS, 18 had DM, 17 had cancer, eight had COPD and one had had an MI. Half of the patients had been hospitalized via emergency units, while most of the others (47.1 percent) had been admitted via outpatient services. Only three had been referred to the hospital. The average length of hospital stay was 17 days. The longest stay was 59 days and the shortest was three days. Seven of the patients were still hospitalized by the time the fieldwork was completed. Three patients passed away shortly after being discharged.[1] The interviews and participant observation were carried out by a sociology graduate student and a nursing graduate student. Data were collected from patients and family members. Medical records were obtained with the permission of patients. The average number of interviews (with different people) per patient was 5.1. The patient interviews provided data on illness experience, help-seeking behaviour, knowledge and explanation of the illness, treatments, prognoses and a host of other information.

Table 1 presents the demographic and medical characteristics of the patients in the study. Of the 70 patients, 18 were from the medical centre, 23 from the area hospital, while 29 were from the regional hospital. There were 32 males (45.7 percent) and 38 females (54.3 percent). Half of the patients were 60 years old or over. The majority of the patients (82.8 percent) had six years of education or less. Thirteen patients (18.6 percent) were the principal

Table 1 Patient Characteristics

	Teaching Hospital N *(%)*	*Area Hospital* N *(%)*	*Region Hospital* N *(%)*	*Total* N *(%)*
Sex				
Male	5 (27.8)	13 (56.5)	14 (48.3)	32 (45.7)
Female	13 (72.2)	10 (43.5)	15 (51.7)	38 (54.3)
Age group				
<39	5 (27.8)	2 (8.7)	0 (–)	7 (10.0)
40–49	0 (–)	1 (4.4)	4 (13.8)	5 (7.1)
50–59	4 (22.2)	8 (34.8)	12 (41.4)	24 (34.3)
60–69	7 (38.9)	5 (21.7)	4 (13.8)	16 (22.9)
70+	2 (11.1)	7 (30.4)	9 (31.1)	18 (25.7)
Occupation				
Unemployed	3 (16.7)	3 (13.0)	12 (41.4)	18 (25.7)
Housewife	6 (33.3)	9 (39.1)	4 (13.8)	19 (27.1)
Blue-collar	5 (27.8)	8 (34.8)	9 (31.0)	22 (31.4)
White-collar	3 (16.7)	2 (8.7)	0 (–)	5 (7.1)
Business	1 (5.6)	1 (4.4)	4 (13.8)	6 (8.6)
Education				
Literacy	7 (38.9)	9 (39.1)	17 (58.6)	33 (47.1)
Grade school	1 (5.6)	13 (56.5)	11 (37.9)	25 (35.7)
Junior	1 (5.6)	0 (–)	0 (–)	1 (1.4)
Senior	4 (22.2)	0 (–)	0 (–)	4 (5.7)
College	5 (27.8)	1 (4.4)	1 (3.5)	7 (10.0)
Entry port				
Outpatients Department	4 (22.2)	15 (65.2)	14 (48.3)	33 (47.1)
Emergency	12 (66.7)	8 (34.8)	15 (51.7)	35 (50.0)
Referral	2 (11.1)	0 (–)	0 (–)	2 (2.9)
Diagnosis				
Diabetes	3 (16.7)	7 (30.4)	8 (27.6)	18 (25.7)
COPD	0 (–)	2 (8.7)	6 (20.7)	8 (11.4)
Cancer	9 (50.0)	3 (13.0)	5 (17.2)	17 (24.3)
CVA	6 (33.3)	9 (39.1)	10 (34.5)	25 (35.7)
MI	0 (–)	2 (8.7)	0 (–)	2 (2.9)
Total	18 (25.7)	23 (32.9)	29 (41.4)	70 (100)

family breadwinners, but 57 patients (81.4 percent) were not. Their living arrangements vary: over half of the patients (39, 55.7 percent) were in an extended family, 26 (37.1 percent) in a nuclear family and five (7.1 percent) live by themselves.

Life in the Hospital

A great majority of the patients in this study received care from private sources. When we counted a family member as a caregiver, the family companion had stayed with the patient and rendered services and care to them. Among the 70 patients, only six patients (8.6 percent) had no bedside caregivers, 46 patients (65.7 percent) had bedside caregivers 24 hours a day, seven patients (10 percent) only during daytime, 1 patient (1.4 percent) only during evening and ten patients (14.3 percent) had caregivers irregularly.

Family caregivers constantly monitor the conditions of the patients. They are first-hand observers of the treatments and care rendered to the patients. They console the patients when necessary. They help patients in having food (including nasal feeding), taking medicine, bathing and using bedpans. Bedside caregivers also assist the medical staffs by serving as interpreters and as negotiators between doctors and patients. They act as information providers to the patients with regard to diagnoses and treatments. They report to the nurses the status of intravenous drips and if there is a need for suction.

Many patients rely on their families to bring in meals, either cooked by their families or ordered from restaurants or eateries outside the hospital. The food that is brought in reflects the traditional Chinese conception of nutrition for the ill. According to Chinese folk wisdom, it is essential to drink a specially prepared soup when a person is sick. This kind of soup is not available in any modern hospital where western trained nutritionists are in charge of meal plans.

Taiwanese hospitals have many institutional arrangements designed to facilitate the participation of private caregivers in patient care. Private caregivers are allowed to stay overnight with patients, except for patients staying in the intensive care unit. Considering the comfort of the caregivers and the tidiness of the ward environment, some hospitals even provide fold-up beds. Nurses teach private caregivers how to care for the patients, including nasal feeding, turning, suctioning and washing.

Because of their dependence on intensive family care while in hospital, patients often suffer from stress and guilt: 'It is very uncomfortable to stay in the ward with me over night. They [the patient's son and daughter-in-law] don't even have a bed on which they can lie down. They have to work during the daytime', explained Mrs Chen, a 57-year-old diabetes patient. Some of them commented on how lucky they are to always have a family member at their bedside, saying 'This is the time to enjoy the advantage of having raised many offspring.'

Personal interactions between medical staff and patients were rare. Our fieldwork was a welcome 'intrusion' for the patients and their families. They shared with us their sadness, anxiety, queries, complaints and joy of recovery.

Many patients and their family members expressed their gratitude: 'Thank you for spending time with us. It has been nice to have someone here to talk with in the hospital.' Two of the patients in this study were reluctant to accept our visits. One patient's family thought the interviewers were insurance sales agents, while the other was too worried about the patient to grant any interview. The research team later developed a good relationship with both patients and their family members during the data collection period.

Mobilization of Family Resources

How does a Taiwanese family decide on who does what in the hospital care of its member? Drawing on my in-depth interviews, I examine the interpretations of the patients and their families, the objective contexts around which the families mobilized resources, and the actual decisions they made regarding family involvement in hospital care. The wealth of information would provide the basis for an evaluation of the empirical support for the strong family and weak hospital hypotheses. Seven findings are most pertinent.

Significance of the Marital Tie

What are the conditions for the primary caregiver to come from the nuclear family? Family structure often affects whether the mobilization of family resources extends beyond the boundary of the nuclear family. In general, a patient's spouse would take primary responsibility for the care regardless of the patient's gender so long as the patient's spouse was relatively young (Table 2). Twenty-seven patients' major caregiver was their spouse. Twenty-two of the patients were under 49 years old. Those who had spouses but were cared for by someone younger in terms of kinship status (namely sons and daughters) were elderly patients (older than 60 years of age). For elderly patients with or without living spouses, the responsibility of care would fall on adult children, especially those who lived close to the hospital. The spouse of an elderly patient would retain the primary responsibility if the children were too young or if the adult children were employed full-time.

Work status matters, too. If both the spouse and the adult children were working, they would share the responsibility. If it was not too costly for the spouse to take leave from work or even quit their job, the spouse would do so and assume the role of bedside caregiver. Adult children would share the care after work. If the adult children were able to handle the care, the spouse would generally play a minor role and attend to the patient only at critical times.

The care arrangements for Mrs Ko illustrate how some of the aforementioned key principles work in practice. Mrs Ko, 39 years old, was diagnosed with cancer. Her husband was a trader in a traditional local market. He closed his shop in order to take care of his wife full-time. They have two

Table 2 The Relation of Major Caregiver to the Patients, by Patient Characteristics

	Age			*Sex*		*Marital Status*				
	<49	*50–59*	*60+*	*Male*	*Female*	*Single*	*Married*	*Widowed*	*Separated*	*Total*
Nurse-aide	1	1	6	4	4	1	2	3	2	8
	(14.3)	(20.0)	(10.3)	(12.5)	(10.5)	(33.3)	(4.1)	(21.4)	(50.0)	(11.4)
Spouse	4	1	22	10	17	0	26	0	1	27
	(37.9)	(20.0)	(57.1)	(31.3)	(44.7)	(–)	(53.1)	(–)	(25.0)	(10.0)
Elder,[a] M	0	0	0	0	0	0	0	0	0	0
	(–)	(–)	(–)	(–)	(–)	(–)	(–)	(–)	(–)	(–)
Elder,[a] F	0	1	1	1	1	0	2	0	0	2
	(–)	(20.0)	(1.7)	(3.1)	(2.6)	(–)	(4.1)	(–)	(–)	(2.9)
Same,[a] M	1	0	1	2	0	0	1	1	0	2
	(14.3)	(–)	(1.7)	(6.3)	(–)	(–)	(2.0)	(7.1)	(–)	(2.9)
Same,[a] F	1	1	3	3	2	1	2	0	2	5
	(14.3)	(–)	(1.7)	(6.3)	(–)	(–)	(2.0)	(7.1)	(–)	(2.9)
Young,[a] M	1	2	27	15	15	0	18	10	2	30
	(14.3)	(40.0)	(46.6)	(46.9)	(39.5)	(–)	(36.7)	(71.4)	(50.0)	(42.9)
Young,[a] F	0	2	25	10	17	0	19	7	1	27
	(–)	(40.0)	(43.1)	(31.3)	(44.7)	(–)	(38.8)	(50.0)	(25.0)	(38.6)
Total	7	5	58	32	38	3	49	14	4	70
	(10.0)	(7.1)	(82.9)	(45.7)	(54.3)	(4.3)	(70.0)	(20.0)	(5.7)	(100.0)

[a] Comparison in terms of kinship status.
Percentages in parentheses.

young children. He had financial problems, but chose to care for his wife himself. He reasoned as follows: 'How can I choose to make money at this moment and have someone else to take care of my wife in the hospital? People would say I love money more than my wife.'

Intergenerational Caring

Although all patients in this study received care from their families in different formats and to varying degrees, the sources of care are not evenly distributed. One of the most notable patterns is that intergenerational help is more common than intragenerational help. The mobilization for help often extends vertically in two directions, that is to the parents and children, but not horizontally to siblings. Intragenerational caring is seldom observed except between spouses. Care is a matter of intra-family responsibility when a patient's family consists of multiple generations. The vertical relationship of father–son remains the strongest family tie (Wen, 1991). Both parents and children recognize the duty of care, while siblings consider it optional. When a sibling is hospitalized, nothing more is expected of the other siblings than to pay visits. Mrs Ko is a typical example of this pattern. While her husband took full responsibility for her care, her brothers and sisters came to visit her in the hospital frequently and left 'red envelopes' (monetary gifts) occasionally. No one shared the husband's burden of care.

However, the roles for the old and young generations are asymmetric. The older generation seldom become primary caregivers, regardless of the sex or marital status of the patients (Table 2). Thirty patients had younger (in terms of kinship status) men as primary caregivers, while 27 had younger women. In contrast, few patients rely on someone of the same generation (other than their spouses) for primary care (two male and five female patients in our sample), and only two patients had elder (in terms of kinship status) women as caregivers. No older male relatives were involved in care.

As far as the asymmetry between the old and young is concerned, a moral obligation appears to be at work. Chinese citizens seem to feel morally responsible for the care of their parents, including the parents of their spouses. Intergenerational exchange is emphasized. For instance, Mrs Young (a 66-year-old diabetic) has five sons and four daughters. They were all married. Mrs Young's eldest son drew up a timetable for all the family members, including her adult grandchildren. He did this in order to ensure that there was always at least one family companion in the ward: 'People tend to offer help at the most convenient time for themselves, and so there is a chance that no one offers help at certain time slots.'

A Gender Issue?

Although it is common to observe daughters caring for mothers, gender-specific obligations are not clear. Male patients tend to be more likely to have

young males as major caregivers, while females have young females (Table 2). As Mr Lu's sons put it: 'It is not convenient to have our wives coming to care for our father. After all, they are women.' Mr Lu, 76 years of old, suffers from diabetes. He has two sons and five daughters. His sons took it in turns to care for him.

Although major caregiving is not necessarily gender specific, and while both men and women are involved in caring for the patients in the hospital, the content of the care is gender related. There is a division of labour by gender in terms of the content of care given. Women are in charge of caring, while men deal with the communication with doctors and taking care of any relevant paperwork. Women prepare the meals for the patients, while men stay at the patient's bedside.

Married Daughter, 'Spilled Water'?

A married daughter plays an ambiguous role in caring for her parents. The source of the ambiguity is the Chinese idea that when a daughter is married, she belongs to her husband's family – she's spilled water. With regard to intensive care for parents, a married daughter is perhaps more responsible for her husband's parents than her own parents. By the same token, a daughter-in-law is always an eligible source of hospital care for the parents-in-law.

The actual involvement of married daughters is highly variable. In some cases, the responsibility of bedside care and health expenses are equally shared among sons and daughters, regardless of marital status. In other cases, the sons' families take turns in caregiving and also pay the hospital expenses, while married daughters help with expenses in exchange for an exemption from bedside care. Sometimes a married daughter may take a daytime shift when her husband is at work and does not share the health expenses, while sons assume the night shift and the burden of expenses.

In still other cases, married daughters only visit, while the sons take full responsibility for the care of the hospitalized parent. A married daughter is no longer considered a family member whom a parent can rely upon in a family crisis. 'She [her daughter] has married out. She is now a member of her husband's family. She no longer belongs to us', said Mrs Wong. She was concerned that her son-in-law (or his parents) would be displeased if her daughter stayed in the hospital to take care of her. However, when care and health care expenses are borne solely by the sons, there is often tension between daughters-in-law and married daughters. 'When my mother is sick, I share the care and health expenses, too. Why should they [her sisters-in-law] get away with it when their father is ill?', a patient's daughter-in-law complained. Conflict and tension are common between parents-in-law and daughters-in-law, between daughters-in-law and married daughters, and among daughters-in-law.

Table 3 Bedside Care Arrangement and the Ability to Self-Care

	24-hour	*Daytime*	*Evening*	*Irregular*	*None*	*Total*
No ability	28	1	1	0	0	30
	(93.3)	(3.3)	(3.3)	(–)	(–)	(42.9)
No ability after operation	5	0	0	0	0	5
	(100.0)	(–)	(–)	(–)	(–)	(7.1)
Able but weak	10	2	0	1	1	14
	(71.4)	(14.3)	(–)	(7.4)	(7.4)	(20.0)
Fully able	3	4	0	3	11	21
	(14.3)	(19.1)	(–)	(14.3)	(52.4)	(30.0)
Total	46	7	1	4	12	70
	(65.7)	(10.0)	(1.4)	(5.7)	(17.1)	(100.0)

$\chi^2 = 44.8$, $p < .000$
Percentages in parentheses.

Patients' Ability to Care for Themselves

Not every patient has a carer at their bedside from the very beginning of their hospitalization. Constant and intensive bedside care may start in the middle of hospitalization. Bedside care may also stop at a point before full recovery. The patient's 'ability to move around' appears to be the most critical criterion in deciding whether a bedside caregiver is necessary. The aftermath of a surgical operation, the transfer from the intensive care unit to a regular ward, or the presence of debilitating conditions tend to necessitate a constant companion, and family members ensure that continuous bedside care is organized. But unless necessary, a patient does not want their relations to carry the burden of constant care; as 57-year-old Mrs Chen, mother of three sons and two daughters declared:

> I don't want them to come to the hospital. I can move around now. I can eat. All I need to do is to control the level of my blood sugar at this moment. I can take care of myself in hospital. They all have work to do. It is sufficient for them to visit me once in a while. I know they will be with me as I need them.

Against this background, variables such as age, sex, severity of illness, status in the family and diagnosis are included in this study to examine their respective impact on the bedside care arrangements. Here 'severity of the illness' is defined in terms of the patient's ability to care for him- or herself. The results indicate that the ability to care for oneself and the diagnosis are the only two variables which vary significantly with the bedside care arrangements (Table 3). These two variables are highly correlated. As shown in Table 3, those who have surgical operations and are transferred from the intensive

care unit and who cannot care for themselves have bedside carers 24 hours a day. Only one patient had one caregiver during daytime, and another just for the evening. For those who do not have family members, or whose family members have jobs, hiring round the clock nursing care becomes a logical solution. Such arrangements change after the patient feels much better and can move around.

In contrast, those who are able to take care of themselves tend to have fewer caregivers. Those who are weak and can only partially care for themselves still have 24-hour bedside care (71.4 percent vs 65.7 percent of the total sample), while only one patient in this state had no one. In other words, when the patient can take care of him- or herself, the family may only fit caring for them around their own daily schedules. Mrs Wong, a 68-year-old cancer patient, is a case in point. Her only son took one day off to be with her in the hospital. After he was sure that Mrs Wong was able to take care of herself, her son returned to work on the next day and came during his lunch hour. Mrs Wong's daughter-in-law came after work and stayed for a time before going home.

A Cost-Minimizing Approach

Employment status appears to be a critical factor in terms of who assumes inpatient care. The group most likely to take responsibility for their hospitalized relatives are the unemployed and single, followed in decreasing proportions by those who are unemployed and married, those employed and single and finally those who are employed and married. For instance, Mr Chen (89 years old), Mrs Wong (87 years old), and Mr Kou (65 years old) were all taken care of mainly by their sons, while Mrs Fu (77 years of old) was cared for by her daughters. A common denominator is the fact that their respective sons or daughters were unemployed at the time the patient was hospitalized. Mr Chen's son had closed down his business a year before and was not employed when Mr Chen was hospitalized. Mr Chen's daughter-in-law had to work and took care of the mother-in-law, while his son spent most of the time in the hospital. Mr Chen's grandchildren are the main breadwinners in the family. Mrs Wong's only son was retired. He was the principal caregiver while Mrs Wong was in hospital, while her daughter-in-law and married daughters helped out occasionally. Mr Kou, a cancer patient, has five sons and four daughters. His second son took care of him, because the second son was unemployed. Similarly, Mrs Fu has no son, but five daughters, three of them living nearby. They are all married. The arrangement was as follows: the third daughter took the night shift, while the eldest and the fifth daughter took turns to do the day shift, because the third was employed full-time.

Marital status in relation to family responsibility appears to be the second most important variable in determining who assumes the major responsibility for care. Mrs Young, a 75-year-old CVS patient, has seven sons and two

daughters. The sixth and seventh sons took turns to stay with her in the hospital, because 'they (the sixth and seventh sons) are still single and don't have a family to look after.' Another patient, Mr Lin, lives with his wife and youngest daughter, who is single. When Mr Lin was hospitalized for COPD, his youngest daughter took the major role in caring for him after work and left Mr Lin alone during the daytime, because 'my wife has to do the housework. I can ask nurses for help during daytime.'

Institutionalizing the Hiring of Paid Nurse-Aides

Family members emphasize the stress of providing bedside care under time and energy constraints. Some of them mention that they underestimated the amount of time and energy the bedside care would entail. Finding a nurse-aide and setting specific time slots for family members are the most common strategies used. Mr Kou's family, for instance, first decided to take turns in caring for the patient themselves. But after having cared for Mr Kou for several days in the hospital they opted to hire a nurse-aide. They considered the expense of the nurse-aide's services well worth the money, given the time and energy consumed.

A paid nurse-aide has been institutionalized for those patients who need one, whether or not that patient has a family member at hand. Advertisements for nurse-aide agencies are allowed to circulate around the wards, and the nurse station keeps a hotline number. Services by individual nurse-aides are organized into two shifts. Morning shifts run from 7 a.m. to 7 p.m., while the evening shift starts at 7 p.m. In 1990–1, the rate for a single shift was NT$900 (equivalent to US$36).[2] The expense of a nurse-aide is considered to be an 'extra service', not medically essential, not covered by insurance and not tax-deductible.

Most hospitals put the paid nurse-aides under supervision. Nurse-aides are required either to be in uniform and/or to wear a badge when on duty, even though they are not hospital employees and are not on the hospital payroll. They report to the nursing staff whenever they are not with the patient. The patient hires the nurse-aides. The hospital acts as an agent/broker between patient and nurse-aide. The way in which a hospital supervises nurse-aides implies that the hospital feels morally responsible when the patient stays in the hospital and is in the hospital's custody, although it is by no means a legal responsibility.

Strong Family or Weak Hospital?

What is the underlying force that gave rise to this practice of bedside care among Taiwanese families when a member becomes hospitalized? A cultural approach would emphasize the strength of the Chinese family, whereas an

organizational approach would stress the weakness of the health care system in Taiwanese hospitals. In a Chinese society adult children often demonstrate a strong sense of obligation towards the elderly (Y.-H. Chang, 1994; Chen, 1993; Rho, 1987; Wen, 1991): the family is expected to provide 'around the clock care and services' to the ill (usually the ill are also the elderly). Accordingly, family involvement in Taiwanese hospital care is just an extension of the traditional obligation to the elderly and the ill. Moral obligation is the crucial reason for the involvement of the family in hospital care (Poirier and Ayres, 1991; Miller, 1994). There are, however, empirical patterns that may be difficult for this cultural perspective to interpret: the lack of consensus on the arrangement of bedside care, tension and conflict among family members, the use of cost-minimizing approaches by the family and the emergence of the paid nurse-aide.

First, the allocation of responsibility appears to follow a contingent rather than a uniform principle. The assistance a patient may get from the family depends not only on gender composition (Matthews, 1987; Matthews and Rosner, 1988) and the number of children (Spitze and Logan, 1990) in a family but also on the patient's ability to care for him- or herself. It is the condition of the patient which determines how and when the care is arranged. The patient's ability to take care of him- or herself is critical in determining whether a bedside caregiver is required. It is more likely that family care will be arranged if a patient is not able to care for him- or herself. Moreover, it is also difficult to know from casual observation who is supposed to be the primary caregiver. Caregivers may be a spouse, daughter/son, daughter-/son-in-law, sister/brother, parent, or nurse-aide. A further complication is that most patients receive care from more than one type of family members (mean = 1.44). What kinds of moral codes would determine how different generations and sexes divide their labour in helping the ill and produce such diverse outcomes across situations and families?

Second, tension and conflict do emerge during the mobilization of family resources. It is not at all rare for there to be a dispute over the division of labour between unmarried and married, sons and daughters, and between married daughters and daughters-in-law. The basic familial institutions, descent line and *chia* (family) and intergenerational contracts have changed in postwar Taiwan (Hsieh and Chuang, 1985). The Chinese family system in Taiwan appears to be in a transitional stage, where there is no apparent consensus on the obligation and responsibility of different family members. The status of daughters and their obligation in the family are complicated by their marital status. If a cultural norm or consensual moral obligation used to drive the intense family involvement in hospital care, it is no longer obvious that it is still the main driving force.

Third, the approach families adopt when arranging care for a hospitalized relative is one of cost minimization. Family members minimize the loss

of productivity by dispatching the most available (the unemployed and the lowly paid) and those on whom there will be the least impact (the single) to assume the major responsibility for providing care. Principal caregivers are those who are the most available members in the family, who have the least formal job responsibility in the family – a retired husband, full-time housewife, part-time employed sister-in-law, unemployed youngsters, or students in the middle of the summer break, for instance. The intensive involvement of family members in the provision of care implies a high social cost due to the loss of productivity. The cost-minimizing approach taken by families in inpatient care arrangements points to the inherent resource constraints of the contemporary family to maintain moral obligations to one another.

Fourth, the hospital, as Rosenberg (1987) contends, is a setting where strangers render care for strangers. Many patients mentioned the uneasiness and awkwardness of being cared for by strangers in uniform. Nonetheless, the uniform syndrome is by no means the key reason to include family in inpatient care so extensively, because a paid nurse-aide, another uniformed stranger, is accepted as a substitute for family members. The emergence of the paid nurse-aide provides evidence of the compromise that families must make when a family member is ill and none of the other members are available to provide constant care.

To put it differently, the mobilization of family resources for hospital care is a conjectural process that may not square well with a cultural perspective. Instead, it may fit well with an alternative hypothesis for the central question of this study: whether family involvement is a pragmatic adaptive strategy of the Taiwanese family confronted by the problem of inadequate hospital care.

Hospitals are institutions where strangers render medical care to strangers (Rosenberg, 1987). An increasing coldness and impersonality characterize the social organization of hospital care. Medical practitioners and patients interact in an environment where technical and bureaucratic languages reign even though medical care is intrinsically personal and private. In the relationship between medical practitioner and patient, the former is considered as an agent and the latter a principal whom the agent serves. The relationship between principal and agent is primarily constructed on the basis of impersonal trust buttressed by professional control and bureaucratic management. In this environment of strangers, one readily observes how patients mobilize social connections to enhance the prospect of their well-being (L.-Y. Chang, 1997).

The hospital is an alien environment where daily needs are truncated. The content of care rendered within hospital is highly concentrated on medical treatment. Both patients and their families expressed uneasiness about hospital life. Family members are therefore brought in because their care is very personal and private. As one patient put it, 'The care becomes so intimate,

trustworthy, and unobtrusive when my wife provides it.' The presence of a family member helps relieve the sense of alienation and the anxiety that many patients feel. This by no means suggests that patients do not trust hospital staff. Rather, patients and their families in general tend to totally submit to the authority and practices of physicians and hospital staff (L.-Y. Chang, 1993). Patients and their families do have reservations about the way hospital care is organized – patients do not believe that they can get what they need without the help of family members.

What is observed in the inpatient care is that both patients and their families develop strategies of self-help, because 'busy' is the word used to describe the stance of the nurses on duty, while 'rarely see my doctor' is what they say about their physicians. The nurses' tasks are portrayed by patients as temperature reading, changing intravenous drips, distributing prescribed medicine, arranging for diagnostic tests, finding a paid nurse-aide (upon request) and processing paperwork. Occasionally, they provide health education. Consequently, the hospital seems unable to meet patients' needs as human beings. Life in the hospital becomes impossible without help from those other than the health professionals. 'They [nurses] always rush in and out. It is very difficult to get hold of them to ask for anything.' One thus has to depend on the family for routine care and services: 'They [doctors and nurses, or other hospital staff] are so busy, how could you expect them to handle those things [i.e. feeding, suction, cleaning, changing bed linen and turning] for you? You have to have family accompany you, there is no way you can rely on nurses', one patient's family commented. Patients turn to others, instead of nurses, for the time they are left alone in the ward and need help: 'I send them [patient's family] home, [because they have to work during the daytime]. After all, other patients' families are always around. I believe I can get help from them if I have an urgent need.'

Taiwan has undergone dramatic social change over the last four decades. The extended family is fading as time goes by (Y.-H. Chang, 1994). When a member becomes ill, it generates tremendous pressure on other family members. The contemporary family in Taiwan is constrained by a shortage of human resources. External support is not always available. Although people feel more comfortable when care is rendered within an intimate relationship and people feel obligated to care for the family member in need, family involvement in inpatient care is nonetheless a value-driven behaviour.

Conclusion

This article shows that the family is urged to take part in inpatient bedside care. We assert that the intensive and extensive involvement of families in

inpatient care is an adaptation of the patient's family in coping with a need created by the level of care provided by the hospitals. It is an adaptation to cope with barriers to communication between medical staff, mainly doctors and patients, and also to the fragmentation of the hospital care. Facing the way care is arranged in the hospital, the practice of moral obligation is shaped under the constraint imposed by the family system and the labour market of contemporary society. Hospital care as organized in Taiwan generates additional social costs that deserve more attention by health care professionals and policy-makers.

The strong intergenerational link suggests that filial morality may undergird the caring relationship between adult children and their elderly parents, as Sung (1992) found for Korea. For the Chinese family in Taiwan, Greenhalgh (1988) interprets the Chinese parent–child relationship as a set of unspoken contracts, which lead to expected flows of material and nonmaterial goods and exchanges of rights and duties, or mutual obligations. Making sacrifices for one's children can generate a sense of gratitude and thus the basis for filial obligation (Wicclair, 1990). Nonetheless, it is not clear that gratitude-based obligation is always strong enough for adult children to make the specific sacrifices that may be needed for caring for the elderly ill (Finch and Mason, 1990).

We do not argue that the traditional value of family is unimportant. Rather, we contend that given the overwhelming power of the medical profession in organizing medical care, without the silent permission and latent encouragement from the medical profession in Taiwan, the family would be unable to take part in caring within the inpatient unit. The medical profession retains a dominant position in defining and organizing proper medical care. The social organization of medical care, which mainly reflects the medical profession's conception of medical care, is thus a major determinant of the degree and form of family involvement in inpatient care.

To explore what bedside family caregivers do within the hospital reflects the conception of hospital care as espoused by the medical profession, which can be described as fragmented and incomplete. We argue that family inpatient caregiving is a consequence of a negotiated process between the health professions and the lay person. Due to the way hospital care is organized, the intensive involvement of a patient's family during hospitalization appears to be a remedy for ensuring patients' well-being in the hospital. Both the professional and bureaucratic control of the hospital determines the extent to which the family participates. The medical profession focuses on medical treatment, while the family does what is necessary for the patient to live as a human being. The deep involvement of the family in hospital care is intrinsically an issue of the confrontation of the traditional Chinese family system with the transplanted idea of the western hospital.

Notes

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1 In Taiwan, whenever possible, patients prefer to pass away at home. It is thus still a common practice for dying patients to be discharged in time to die at home.
2 It would have cost US$2160 a month to hire a nurse-aide 24 hours a day, which was equivalent at the time to about twice the average monthly income.

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