

# Experience of Palliative Home Care According to Caregivers' and Patients' Ages in Hong Kong Chinese People

Carmen W.H. Chan, RN, BSN, Mphil, and  
Anne M. Chang, RN, DipNEd, BEdSt (Hons), MEdSt, FRCNA, PhD

**Purpose/Objectives:** To identify the relationship between family caregivers' reported difficulty in managing caregiver tasks and ages of caregivers and patients.

**Design:** Cross-sectional, descriptive survey.

**Setting:** A hospice homecare program in Hong Kong.

**Sample:** Twenty-nine Chinese family caregivers who had experienced at least weekly caregiving responsibility for more than two months and were able to read and understand Chinese.

**Methods:** Respondents completed a caregiver task inventory. Four homecare nurses assisted in the distribution and collection of questionnaires.

**Main Research Variables:** Caregiver tasks and age and patient age.

**Findings:** Caregivers' age was negatively correlated with reported difficulty in overall tasks and in interpersonal ties. The patients' age was negatively correlated with reported difficulty in direct care to patients, intrapersonal tasks, and overall tasks.

**Conclusions:** The younger the caregiver, the more difficulty he or she experienced in the caregiving role, particularly in the maintenance of social and family ties. Caregivers of younger patients experienced more difficulty in most aspects of caregiving tasks. More research with a larger sample size is required to fully investigate the effect of age on the family caregiving experience and the validity of the caregiver task inventory.

**Implications for Nursing Practice:** Nursing support and preparation to younger caregivers and caregivers of younger patients are suggested in the practice of palliative home care.

In Hong Kong, cancer is the leading cause of death in both sexes and in individuals 45 years or older (Census and Statistics Department, 1997). The mortality rate of cancer increased to 149.5 per 100,000 in 1990, doubling the number since the 1960s (Ho & Wu, 1995). These figures imply that more and more families in Hong Kong have to live with and care for a relative suffering from cancer at home. Family caregivers need to shoulder the tasks of caregiving that may interfere with their existing responsibilities and activities of daily living.

Hong Kong also is experiencing a rapid growth in the aged population (Leung, 1996). Although consistent with world trends, this change is occurring more rapidly in

## Key Points . . .

- ▶ Caregiver tasks are multidimensional and include direct physical care, caregivers' intrapersonal concerns, and the maintenance of interpersonal relationships.
- ▶ Older family caregivers of patients with cancer appear to encounter less difficulty in handling overall tasks and interpersonal ties.
- ▶ Family caregivers of young patients appear to experience more problems in managing overall tasks, direct care, and intrapersonal tasks.
- ▶ Caregivers may benefit from nursing support, particularly young caregivers and those caring for young patients.

Hong Kong than in Europe and the United States (Coward & Serow, 1994). A wide age range of people may have cancer, in general, but the expectation is that they will be older (Boyle, 1994). The process of maturation and aging involves a series of role changes and life transitions; hence, older people are expected to have more life experience. Thus, the question of how caregiving experience may vary with age arises. It is anticipated that the ages of the people with cancer and their family caregivers may have a special bearing on the demand for caregiving.

## Chinese Perspective

Historically, the Chinese family has been an important social institution, with individual members respecting family interests more than their own (Bond, 1996). A traditional Chinese family is guided by filial piety (*xiao*), a virtue that emphasizes total submission to one's parents or elders. Almost all older people in Hong Kong were raised in mainland

*Carmen W.H. Chan, RN, BSN, Mphil, and Anne M. Chang, RN, DipNEd, BEdSt (Hons), MEdSt, FRCNA, PhD, both are assistant professors in the Department of Nursing at the Chinese University of Hong Kong in Shatin, Hong Kong SAR (Submitted December 1998. Accepted for publication May 1, 2000.)*

China (Ikels, 1993). In a contemporary Chinese family in Hong Kong, however, little is known regarding whether family members are still influenced by filial piety in terms of caring attitude and caregiving behaviors (Holroyd & Mackenzie, 1995). The infiltration of Western values into contemporary Hong Kong culture, with the valuing of individual achievement and satisfaction, is likely to have a significant impact on the issue of caregiving (Holroyd & Gibb, 1994). The widespread assumption that Chinese homebound or homecare patients are being cared for as long as they have a family is likely to be based on traditional views of Chinese families. However, this assumption may not be true in a contemporary Hong Kong Chinese family. Holroyd and Mackenzie proposed that despite the influence of traditional thinking and culture, some similarities exist between Chinese and Western perspectives in caring decisions and consequences as a result of the changing kinship networks.

Internationally, healthcare professionals have tended to focus primarily on the cure and care of patients, and less attention has been paid to the needs of the family caregivers. In Hong Kong, formal preparation or ongoing professional care of family caregivers is not evident in the healthcare environment (Chan, 1998). No empirical studies investigating the impact of the age of Chinese patients with cancer and caregivers on the experience of caregiving were found. The purpose of this study was to identify the relationship between caregivers' reported difficulty in managing caregiver tasks and ages of caregivers and patients in Hong Kong Chinese people.

## Literature Review

### Caregiver Tasks

Although caregiver tasks frequently have been included as independent variables in the caregiving literature, differences exist in the meaning and perspectives. One perspective uses activities of daily living (ADL) and instrumental activities of daily living (IADL) to describe caregiver tasks (Given, Stommel, Collins, King, & Given, 1990). This perspective allows the identification of the types of caregiver tasks performed as well as the amount of time spent on each task. In Given et al.'s study, ADL included feeding, dressing, bathing, and toileting, whereas IADL included cooking, transportation, laundry, shopping, and financial management. Besides the types of activities performed, caregiver tasks also were measured by the hours of care provided each day and the amount of assistance received from other relatives. Similarly, Kasper, Steinbach, and Andrews (1994) described the intensity of caregiver tasks as the number of ADLs provided in relation to the hours of care, the duration of caregiving in years, and whether additional caregivers were available.

Using a more comprehensive approach, Clark and Rakowski (1983) presented a categorization of caregiver tasks that were derived from clustering points of consensus based on literature review. They identified three dimensions of caregiver tasks: direct care to the patient, intrapersonal tasks, and interpersonal ties. Direct care to the patient included but was not limited to ADLs. It also included being available, supervision of treatment regimen and patient's resources, and providing structure for patient's daily activities. Intrapersonal tasks mainly were concerned with the psycho-

logical stages of caregiving regarding when and where individual caregivers experienced personal and emotional needs. Intrapersonal items incorporated compensating for personal time, resolving uncertainty, and emotionally accepting the patient's poor prognosis. Interpersonal ties involved the familial and social tasks of the caregiver that happened between individuals and others. Items included maintaining knowledge of reimbursement mechanisms, interacting with healthcare professionals, and managing feelings toward other family members who do not offer help regularly. In the current study, this three-dimensional approach to caregiver tasks was used.

### Age and Caregiving

Most caregiving literature contemplated the caregiver's background, including age, on the caregiver's general experience of stress and strain. Schumacher, Dodd, and Paul (1993) studied strain and depression among family caregivers of patients receiving chemotherapy. They found that caregivers of younger male patients were more strained. However, generalization of the results was limited by a disproportionate number of patients with breast cancer (more than 60%). Spaid and Barusch (1991) studied 131 spouse caregivers of chronically ill elderly people. Older caregivers had reported a lower sense of strain. However, this study focused on elderly patients with dementia or general frailty, and patients with cancer were not included. In another study, four elderly caregivers (age 85 and older) recited great satisfaction and little role strain and conflict in the long-term home care of their frail and old relatives (Kim & Keshian, 1994). All four care receivers had neuromuscular disorders and chronic illnesses other than cancer. Most published caregiving studies were conducted in North America or Europe. A need exists to explore the ascendancy of patients' and caregivers' ages on the individuals' experiences of caregiving within their cultural context, as the latter may affect their discernment of and feelings deriving from the tasks of caregiving.

## Methods

The study employed a quantitative and cross-sectional survey approach. Descriptive statistics using the Statistical Package for the Social Sciences for Windows® program (Coakes & Steed, 1997) and nonparametric statistical tests were employed for the analysis of small sample data. An alpha level of 0.05 was adopted for all statistical tests.

### Sample

The researcher approached the first and only freestanding hospice in Hong Kong to recruit participants. Because hospice home care is at an early developmental stage in Hong Kong and has a limited number of clients, only a few family caregivers of patients with terminal cancer could be studied. Therefore, a convenience sample of 29 Chinese family caregivers (one per patient) of patients with terminal cancer participated in the study. Participating caregivers had experienced at least weekly home caregiving responsibility for more than two months and were able to read and understand Chinese. In the cases of more than one caregiver in a family, the caregiver identified as the most significant or a primary caregiver was selected.

## Procedure

Approval to conduct the study was obtained from the Research and Ethics Committee of the Medical Faculty of the Chinese University of Hong Kong and the hospice. Written consent from fully informed subjects also was obtained. The hospice policy did not allow any nonstaff researcher to approach the client directly; hence, four experienced homecare nurses were asked to assist in the distribution and collection of questionnaires. During regular home visits, the homecare nurse contacted prospective participants in person and explained the purpose of the study and individuals' rights as participants. The questionnaires were distributed to the 29 subjects who consented to contribute and collected one week later. All participants returned the questionnaire, yielding a response rate of 100%.

## Instrument

Reported difficulty of caregiver tasks was assessed using an inventory delineated by Clark and Rakowski (1983) consisting of 45 caregiver tasks. The development of the inventory was based on 19 empirical studies, reviews, and service program reports and covers most of the caregiver aspects as reviewed from the literature. Through discussion among bilingual colleagues, the face validity and cultural sensitivity of the English instrument were established. The bilingual researcher then translated the instrument into Chinese and then back translated. Both the English and Chinese versions of the instrument were reviewed further for clarity and cultural relevance by five nurse educators, four homecare nurses, and five caregivers who met the study criteria. No changes were made to the instrument.

These 45 tasks were grouped into the following subscales: (a) direct care to patient (e.g., being available, ADLs), (b) intrapersonal tasks (e.g., resolving uncertainty and guilt), and (c) interpersonal ties (e.g., interacting with healthcare professionals, financial management) (Clark & Rakowski, 1983). Caregivers were asked to rate the perceived difficulty in managing the tasks on a three-point Likert scale according to whether the tasks were 1 (not difficult), 2 (difficult), or 3 (extremely difficult). The possible range of scores was 45–135 on the whole inventory, with higher scores indicating higher levels of reported difficulty.

The tasks and categories are logical groupings on the basis of face validity (Clark & Rakowski, 1983). Killeen (1990) used the inventory in a study concerning the influence of stress and coping on family caregivers' perception of health as an instrument to measure the care provided to frail elders. However, no information on reliability and validity was reported in either Killeen's or Clark and Rakowski's study. In the current study, Cronbach's alpha for the total scale was 0.86, and the subscales ranged from 0.67 (direct-care subscale) to 0.77 (interpersonal ties subscale) to 0.81 (intrapersonal tasks subscale).

The participating nurses collected patients' demographic and illness data from the medical records. Caregivers were asked to fill in a demographic form and submitted it together with the completed questionnaire.

## Results

The majority of caregiver subjects were female ( $n = 22$ , 76%) and unemployed ( $n = 14$ , 48.3%). Their ages ranged

from 29–84 years, with a mean of 50.8 (median age was 50). Table 1 presents other caregivers' demographic data. Spearman Rank-Order correlation coefficients were used to identify the relationships among caregivers' age, patients' age, and caregivers' reported difficulty in managing caregiver tasks. The caregivers' age was found to be negatively correlated with their reported difficulty in overall tasks ( $r_s = -0.38$ ,  $p < 0.05$ ) and interpersonal ties ( $r_s = -0.39$ ,  $p < 0.05$ ).

The majority of patients were male ( $n = 16$ , 55%), and their ages ranged from 15–88 years, with a mean of 64.2 (median age was 68). Eleven patients (8%) had cancer of the respiratory system, and another 11 patients (8%) had gastrointestinal system cancer. Table 2 presents other patient demographic data. The patients' age was found to be negatively correlated with the caregivers' reported difficulty in direct care to patients ( $r_s = -0.45$ ,  $p < 0.05$ ), intrapersonal tasks ( $r_s = -0.53$ ,  $p < 0.01$ ), and overall tasks ( $r_s = -0.49$ ,  $p < 0.01$ ). Table 3 presents a summary of the correlations.

Both caregivers and patients were divided into two groups according to their median age and comparisons made of the reported difficulty of tasks using Mann-Whitney U tests. No significant differences in reported difficulty of tasks were found between the younger than 50-year-old and older than 50-year-old groups of caregivers ( $p > 0.05$ ). For the patients younger than 68 years, the caregivers had significantly more difficulty in overall tasks ( $U = 56.5$ ,  $p < 0.05$ ) and intrapersonal tasks ( $U = 53.0$ ,  $p < 0.05$ ) (see Table 4).

Table 1. Caregiver Characteristics

Characteristic	n	%
<b>Gender</b>		
Male	7	24
Female	22	76
<b>Duration of caregiving</b>		
1–5 months	5	17
6–11 months	11	38
12–24 months	5	17
More than 2 years	6	21
More than 5 years	2	7
<b>Marital status</b>		
Single	6	21
Married	21	72
Widow	1	3
Missing data	1	3
<b>Occupational status</b>		
Unemployed	14	48
Full-time	12	41
Part-time	3	10
<b>Relationship with patient</b>		
Wife	9	31
Husband	5	17
Daughter	10	35
Son	3	10
Other relatives	2	7

N = 29

**Table 2. Patient Characteristics**

Characteristic	n	%
<b>Duration of illness</b>		
1-5 months	2	7
6-11 months	7	24
12-24 months	7	24
More than 2 years	4	14
More than 5 years	1	3
Missing data	8	28
<b>Cancer types</b>		
Respiratory system	11	38
Gastrointestinal system	11	38
Reproductive system	3	10
Neurologic system	3	10
Missing data	1	3
<b>Marital status</b>		
Single	1	3
Married	26	90
Widow	2	7
<b>Gender</b>		
Male	16	55
Female	13	45

N = 29

### Discussion

Correlational findings of this study indicated that older caregivers experienced less difficulty in overall tasks and interpersonal ties, whereas caregivers of younger patients encountered more difficulty in direct care, intrapersonal tasks, and overall tasks. Inferential statistics did not show any differences between the two age groups (younger than and older than 50 years old) of caregivers, possibly as a result of the young cut-off point of 50 years in this study.

The results of this study were consistent with previous findings of Spaid and Barusch (1991), Killeen (1990), and Given et al. (1990), who found that older caregivers felt less strained in caregiving. This finding may be because of older caregivers' diminishing social circle and activities, leaving them more time for caregiving. They may be retired and have less role strain related to work. In addition, older caregivers usually have contacts with friends and relatives whom they have known for years. These kinds of contacts may require less effort and energy than meeting new friends. On the other hand, younger caregivers generally are more likely to have multiple roles, such as par-

ent, student, employee, or breadwinner. With the added responsibility of caregiving, younger caregivers may find it exhausting to maintain the required social and familial ties. Consequently, with less time for caregiving and other activities, they may reveal more difficulty in managing the caregiver tasks and greater susceptibility to role overload.

Consistent with previous findings (Given et al., 1990; Schumacher et al., 1993), caregivers of younger patients in this study experienced more dilemmas in their caregiving experience. One interpretation could be that people in general would see the diagnosis of terminal cancer as more devastating in younger people than in elderly people. Caregivers may find it painful to see a young and ill family member lose so many life opportunities, such as marriage, employment, or parenthood, because of physical limitations or a shorter life span. This is supported by the finding that caregivers of younger patients in this study had tremendous difficulty in managing intrapersonal tasks that included resolving inner feelings toward the patient and the illness (Clark & Rakowski, 1983). Caregivers may not know how to console or find meaning in the terminal illness of a young sufferer. On the other hand, some caregivers may find a need to return the care previously given by the now elderly patients (Musolf, 1991). Showing filial piety to parents or an older family member is highly praised in the Chinese culture (Chang, 1995). Therefore, caring for an older family member seems to be a natural and meaningful responsibility for most caregivers. Older people also may have completed most significant life events and follow a socially defined timetable of human life. Therefore, with the social and cultural assumptions and expectations regarding death and aging, caregivers of younger patients, when compared with those of older patients, might find their caregiving experience to be more perplexing and demanding.

In association with the emphasis of self-sufficiency and active lifestyle in the younger generation (Turner & Pearlin, 1989), caregivers appeared to have more hindrance in providing physical care to a young family member. A young adult patient who used to be strong and independent may not like to be physically cared for by his or her parents or older relatives. Caregivers may be afraid of exposing patients' bodies during bathing and toileting, as the patients' sense of dignity may be affected. Thus, more obstacles and embarrassment in providing physical care to younger patients would be discerned by the caregivers. However, the underlying reasons for the difficulty in providing direct care to a young patient becomes an area of interest for further exploration.

**Table 3. Correlations Among Patient Age, Caregiver Age, and Caregiver Tasks**

	Caregivers' Age	Direct Care to Patient	Intrapersonal Task	Interpersonal Ties	Overall Tasks
	$r_s$	$r_s$	$r_s$	$r_s$	$r_s$
Caregiver age	-	-0.29	-0.36	-0.39*	-0.38*
Patient age	0.07	-0.45*	-0.53**	-0.32	-0.49**

\*  $p < 0.05$ ; \*\*  $p < 0.01$

$r_s$  Spearman rank correlation coefficient

Table 4. Comparison of Caregiver Tasks Between Patients of Two Age Groups

	Mean Subscale Score	SD	Patient Age < 68	Patient Age > 68	Mann-Whitney U test
			(n = 17)	(n = 12)	
Total tasks (45 items)	1.56	0.32	Mean Rank 17.7	Mean Rank 11.2	56.6*
Direct care to patient (14 items)	1.56	0.26	17.4	11.7	62.0
Intrapersonal tasks (19 items)	1.60	0.30	17.9	10.9	53.0*
Interpersonal ties (12 items)	1.58	0.33	16.3	13.1	79.5

\*p < 0.05

## Conclusions and Implications

The experience of family caregiving to patients with terminal cancer appears to vary according to the ages of caregivers and patients in Hong Kong Chinese people. Despite the aging process, the results of this study accentuate that the older the caregivers, the lesser the difficulty they endured in caregiving. In addition, the younger the patients, caregivers had more problems in managing most aspects of caregiving tasks. With the trends of early discharge from hospitals and the promotion of home care, nurses are assuming a prominent role in working with family caregivers. This study suggests that caregivers may benefit from nursing

support and preparation, particularly for young caregivers and for those caring for young patients. Because this study had a small convenience sample and a cross-sectional design, more research with a larger sample stratified by age is required to fully investigate the effect of age on the palliative home caregiving experience. Empirical studies also are needed to refine and determine the validity of the caregiver tasks inventory delineated by Clark and Rakowski (1983) because the tool was not validated previously.

**Author Contact:** whchan@cuhk.edu.hk with copy to editor at rose\_mary@earthlink.net

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