Caring for family members with stroke: Chinese family caregivers' experiences

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Abstract This study examines the experiences of 15 caregivers from Hong Kong Chinese families who have been attending to elderly relatives with stroke in a home setting. The purpose of this study is to explore and describe, by means of in-depth interviews, the experience in Chinese families of caregiving for victims of stroke. It argues for the distinctiveness of the Chinese caregiving experience in terms of the impact the experience has on many aspects of their lives, such as beliefs, rituals, family structure, emotions, attitudes to illness and problem-solving skills. Interpretive explanations of what the perceived needs were and how they differed among Hong Kong Chinese family caregivers were inductively generated from the data using a qualitative approach. Data were collected utilizing two forms of reflection: interviews and memos. Audiotaped interviews were transcribed. Content analysis was used to analyze the interview data in this study. The researcher classified the data into categories according to the constant comparative method of content analysis. Four key themes emerged as the family caregivers in this study explained their experiences: learning to cope with new demands; managing their own emotional responses; appraising kinship and community support; and maintaining a balance between caregiving needs and their own needs. These themes reflect the impact of caregiving on the Chinese family caregivers in this study and show that providing informal care for stroke survivors represents a significant hidden cost to Hong Kong society.

INTRODUCTION

Stroke is the fourth most common cause of death in Hong Kong. There were about 16,000 cases of stroke and it was also the third leading cause of hospitalization in Hong Kong in 2001 (Hong Kong Hospital Authority, 2002). More than two-thirds of stroke survivors have some degree of physical impairment and are dependent on family members to care for them (Chan & Yeung, 1998; Chiu & Dai, 1996; Ho, 2002). In helping them to make a maximum recovery, and to successfully adapt in the case of a partial recovery, family caregivers have a significant role to play.

The researcher has chosen Chinese family caregivers of people with stroke as the target group for the study because rehabilitation care for stroke patients continues from the hospital to the home setting for months or even for years. It has been well documented that the inclusion of family caregivers in stroke rehabilitation improves recovery (Han & Haley, 1999; Sim et al., 1997; Stein et al., 2003). Besides, over 60% of Chinese family caregivers are elderly spouses and they also have their own health problems (Census & Statistics Department, 2001). A large number of studies have already indicated that caring for dependent relatives at home is burdensome (Abraham & Berry, 1992; Archbold et al., 1990; Ngan et al., 1996; Twigg, 1992; Wright, 1998; Zari, 1989). Such stress may be extreme if the person who is being cared has been a victim of stroke. Thus, family caregivers of people with stroke need appropriate resources to assist them to withstand the
stress and strains arising from the multiple demands, which could last for months and years.

CHINESE FAMILY CONTEXT

It has been well documented that the Chinese, because of the strong impact of their cultural values and tradition, exhibit certain personality characteristics and value orientations which are unique to the Chinese (Bond, 1996; Chow, 2000; Kwan, 2002; Philips, 2000). In many Western societies, individualism is the dominant ideology and a family is often perceived to be a unit consisting of a collection of related individuals. Recent studies have found that there is a hierarchy of family caregiving in Western countries based on a caregiver's kinship relationship to an elderly relative (Draughn et al., 1995; Kerr & Smith, 2001; Wright, 1998). By contrast, Chinese culture traditionally assumes that the family is the basic unit of society. Confucian and Buddhist value systems uphold the perspective that caring for older people is a family responsibility. The mutual obligation that characterizes filial piety has provided a firm basis for the provision of continuing care for frail elderly parents (Bond, 1996). However, norms appear to be rapidly changing in some Chinese communities such as Hong Kong. Globalization, post-modernization and other social forces have influenced long-standing Chinese traditions. Structural changes also appear to be affecting the idea that family members should assume the responsibility of providing care for elderly people (Philips, 2000). It was easier to be filial when families were large and life expectancy short, but it is a bigger challenge when one's parents require long-term care in a post-modern Chinese society with nuclear families that have fewer children. Having health problems, obligations towards one's own family and holding a job are becoming socially acceptable excuses for not assuming a heavy family caretaking role in Hong Kong society. It is also quite acceptable to employ others to care for an ageing spouse or parents.

The researcher argues that caregiving is not solely a task activity, but an activity that includes plans and decisions made by caregivers. These are not observable tasks, and may have important consequences for the lives of the caregivers. Therefore, a good understanding of Chinese family caregiving must involve an appreciation of the cultural context within which events and actions take place, including the 'frames of interpretation', which individuals involved use to evaluate the process.

CHINESE FAMILY CAREGIVING RESPONSIBILITIES

With a predominantly Chinese population and a cultural tradition of respecting the old, Hong Kong has long relied on the family to support its elderly relatives. Most Chinese elderly would rather stay at home and be cared for by family members even if their health is deteriorating. Previous studies have revealed that home care was more relevant for stroke patients and their families than hospital care (Lui & Mackenzie, 1999; Woo et al., 1992). However few services and little support have been extended to family caregivers in the home setting (Chow, 2000; Ngan et al., 1996; Kwan, 2002). Several authors have investigated the responsibilities undertaken by Chinese family caregivers of people with stroke, the difficulties they experience, and the impact of community support groups for them in Hong Kong (Lee, 2001; Lee et al., 2003; Lui, 1997; Lui & Mackenzie, 1999; Mackenzie, Holroyd, & Lui, 1998; Woo et al., 1992). They all found that the impact of caring for stroke patients was traumatic and exhausting. It has been posited that education and support groups can enable these family members to better carry out their responsibilities. However, despite the Chinese family caregivers under utilization of some programmes and services, such as the community stroke support group, patients and family caregivers have not been asked for their opinion on how services should be improved. By listening to the voices and concerns of the caregivers, this study aims to fill this gap in knowledge and use the findings to address community care issues and design programmes to assist family caregivers.

PURPOSE

The main purpose of this study is to explore the experiences of Chinese family members caring for
older relatives who have been diagnosed with stroke, in order to identify the perceived needs of family caregivers and plan appropriate interventions to provide effective support for their caregiving role.

METHOD

This study adopted a qualitative research design since this allows a researcher to proceed inductively and to study Chinese family caregivers and their setting holistically and with sensitivity to the participant’s own frame of reference. In qualitative research, the researcher is concerned with understanding human behaviour from the perspective of the participants. So the researcher seeks to uncover the thoughts, perceptions and feelings experienced by the participants, because qualitative research is most interested in studying how people attach meaning to and organize their lives, and how this in turn influences their actions. The strength of qualitative approaches lies in their capacity to generate rich data regarding a family caregiver’s subjective experience, allowing increased understanding of family motivations and behaviours within stressful situations (Marshall & Rossman, 1989). It is anticipated that the findings of the study would provide a context for understanding the phenomenon of providing care within Hong Kong Chinese society and, hence, for identifying the perceived needs of caregivers. In particular, the experiences of the family caregivers of people with stroke were identified, described, and interpreted.

SAMPLING

The researcher used purposive sampling in this study to investigate the experiences of family members caring for their elderly relatives. Purposive sampling relies on a smaller number of informants deliberately chosen to inform the researcher in detail about personal meanings and perceptions (Streubert & Carpenter, 1995). The criteria for inclusion in this study were: 1) the carer was the dependent person’s relative; 2) the carer was identified by the dependent person as the primary caregiver; 3) the carer had been the primary caregiver for more than six months; 4) the carer was taking care of the dependent person in a home setting; and 5) the dependent person had suffered a stroke.

A total of 15 family caregivers who met the above inclusion criteria provided information for this study. The sampling was drawn from two stroke wards in two hospitals and two stroke support groups in the community of Hong Kong. They all had more than six months’ caregiving experiences in a home setting. Chinese family caregivers in this study consisted of seven wives, five husbands and three daughters. They ranged in age from 27 to 87 years, with a mean age of 62 at time of interview. The majority were originally from Mainland China and had migrated to Hong Kong in the past 10 to 50 years. The remainder were born in Hong Kong. About seventy-five per cent (12 caregivers) of the interviewed family caregivers were elderly themselves, aged over 65. The oldest caregiver was 87 and the spouse of the dependent person. The youngest caregiver was 27 and the daughter of the dependent person. All three daughters had hired helpers in caring for their stroke mothers in this study, but the interviewees were still considered to be the primary caregivers. Two of the daughters of the dependants were working full-time and the other daughter had her own family. Four of the fifteen family caregivers owned their homes. Relatively few family caregivers in this study, three of the fifteen, were in full-time and part-time employment at the time of interview. The remainder were either retired or housewives.

In this study, the in-depth interviews with the family caregivers were scheduled at a time and place convenient to them. All of the interviews took place at the family caregivers’ homes, except for two, which took place in a quiet café at the request of the family caregivers. The duration of each in-depth interview averaged two hours, and the interviews were conducted over a period of three months. In order to validate and enrich the family caregivers’ descriptions of their caregiving experiences, two to three interviews were conducted with each family caregiver. The interviews with all of the 15 family caregivers were tape-recorded, transcribed and typed in Chinese. Rubin and Rubin (1995) say that in a
qualitative interview ‘the researcher gently guides the discussion, leading it through stages, asking specific questions, and encouraging the interviewee to answer in depth and at length’ (p.124). The long interview method stopped when patterns became repetitive in the interview and data were thematically saturated in content analysis.

DATA ANALYSIS

After each interview, a memo with contact summary sheet was completed in the same day the data was collected. As soon as possible after the completion of each interview session, the tape-recorded interviews were transcribed and typed in Chinese. The audiotapes were listened to again to ensure that the transcription of each interview was complete and accurate. Memos were also used to keep track of changes in thoughts about the properties of the categories and the connections between selected categories. Writing analytical notes in the memo and reviewing them regularly was useful for narrowing down the research focus and raising the study’s level of abstraction from a descriptive to an explanatory account through the expansion of key elements, construction of categories and validation.

Content analysis was used to analyze the interview data in this study. This was a systematic procedure whereby verbatim or unstructured data were systematically categorized and constantly compared by content area. Data analysis using the technique of coding was done immediately after each interview had been transcribed. The purpose of coding was to identify essential elements, formulate categories, trace linkages between categories and develop themes.

RESULTS

In describing the results of this study, the experiences of family caregivers were categorized under the various unmet needs of caregiving. Family caregivers with unmet needs were those who had the greatest need of support, but who did not receive it from their children or from other sources in this study. An analysis of the study data revealed that in providing care to their family members, the family caregivers in this study were clearly influenced by the traditional Chinese values discussed earlier. In addition, one outcome of this analysis was the identification of 38 categories of caregiving experiences, which were pertinent to the experiences of family members caring for elderly relatives who had experienced strokes. The meanings formulated from these key elements were clustered into four key themes. They four key themes emerged as the family caregivers in this study explained their experiences on family caregiving: learning to cope with new demands; managing one’s own emotional responses; appraising kinship and community support; and maintaining a balance between caregiving needs and one’s own needs. Issues of culture, tradition, and religion dominated throughout these themes.

Theme 1: Learning to cope with new demands

It has been widely recognized that the caregiving process is stressful and family caregivers adapt to stressors by initiating coping strategies within the family to decrease family vulnerability (Folkman & Lazarus, 1984). In this study, caregivers coped with their situations in different ways and mediating factors such as self-efficacy and the relationship with the cared-for person influenced caregiving outcomes. All of the family caregivers in this study committed and coped with the new demands of caregiving on their own, especially at the beginning of caregiving when stroke relatives were discharged from hospitals. As discussed earlier, it has been assumed in Confucianism that people are essentially benevolent, and this assumption has had a major impact on the various behaviours of the Chinese people. Under the influence of Confucianism and Buddhism, Chinese people have grown up with the belief that the individual should make an effort to return any favours that they owe (Bond, 1996). It has been evidenced that most of the Chinese family caregivers usually lacked the basic techniques to care for their disabled relatives with stroke (Lee et al., Lui & Mackenzie, 1999; Woo et al., 1992). The family caregivers in this study responded to new demands of family caregiving alone by adopting various coping strategies. It was found that older caregivers’ self-efficacy had been identified as one of the predictors of caregiving outcomes in this study.
The following remarks are illustrative:

A 74-year-old woman looking after her severely disabled husband with dementia gives one example:

Every morning I have to wash his face and change the napkin. He is usually doubly incontinent in the middle of the night and I have to get up to check on him and wash him every night. He would grip the bar that had been brought from the hospital. In the end, I would not be able to fall into sleep again. I then get up early and go to the market every morning while he is sleeping. I come home and prepare the meals. It is very tough. (Participant # 9)

A 75-year-old man looking after his wife with moderate disability gives another example of coping:

I felt completely exhausted at the very beginning, as I had to go shopping and prepare the meals. I had to be very careful in taking care that she moved and that I assisted and followed her; I always check her blood pressure; I also go to check and see she is well covered in the middle of the night! In fact everything has to be done quickly, which gives me a lot of stress. (Participant # 1)

In this study, the older spousal caregivers were less likely to seek support from their own family members and/or from services outside the home, whether public or private. In this study, those family caregivers who did not have any children or whose children were living far away were found to have many unmet needs. Younger elderly as opposed to older elderly, and males as opposed to females were more likely to seek instrumental and financial support from both children and other sources. Family caregivers described their caregiving activities as a hierarchy of assisting behaviours: assisting the stroke victim with personal care such as eating a meal, taking a bath, using the toilet, and dressing; providing companionship; handling finances; shopping; providing transportation; and doing the laundry. Some caregivers stated that they themselves no longer had enough strength to cope with the heavy physical work involved in caring for a partner with severe disabilities after one to two years of lifting and transferring. When describing situations in which pressure was experienced, family caregivers indicated that pressure was associated with the person’s inability to walk, the burden of taking care of a person with incontinence, doing the housework without extra help, and with the person’s lack of recovery.

Theme 2: Managing one’s own emotional responses

The physical work and emotional strain led to the exhaustion of caregivers’ own inner resources as reflected by the sacrifice of their health. Some of the family caregivers in this study were able to withstand many months, even years, of strain before they reached complete exhaustion, which all of them experienced. The psychological distress suffered by the family caregivers in this study was linked to the length of time that care was provided, particularly for caregivers with little information and social support. Most of the family caregivers in this study reported feeling under pressure to care for their family members at home. The following remarks are illustrative:

A 67-year-old man with heart disease and a pacemaker looking after his severely disabled wife gives one example:

It was the toughest time when she was immobile and lying in bed. I could not work and did not have any money. I could not think clearly within those six months. I always wanted to end my life when I could not think clearly...I thought of ending my life by jumping down from the building. I always cried and she cried also when she saw me crying. I am a male and it is very difficult for me to do all this housework and care for her... It is embarrassing to change and wash her because I am a gentleman. I found it very tough and it gave me lot of stress and pressure when she was immobile and lying in bed... Gradually she was able to go to the toilet with assistance and I do not have much pressure now. (Participant # 4)
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Theme 3: Appraising kinship and community support

In Chinese society, adult children have traditionally been regarded as the main providers of both instrumental and financial support for the elderly. The reduction in family size in recent years has led to concerns about whether the caregiver’s unmet needs increase. Family caregivers did not readily seek professional help and it might be that the help was not family oriented and it did not meet their family caregiving needs. It is likely that there were groups of families who had no need of professional help to cope with life, though they still require resources and services to help them cope. Individual factors such as age, sex and culture result in different needs being paramount. Older family caregivers tended to hide their problems from other family members; they refused to turn to their families and friends for support and did not seek any professional help. Among the Chinese family caregivers in Hong Kong, paid support was still regarded as the last resort in people’s selection of support alternatives. If support from informal kin were available, the Chinese would not seek paid support, even if they had the financial resources to do so. This could be attributed to the low quality of the paid services available and to the general reluctance to rely on unconnected persons to provide support. However, it is not difficult to see why stroke is called a family illness. Family caregivers in this study that were not satisfied with the resources of their social support reported a greater amount of pressure in their caregiving. The following remarks are illustrative:

A 50-year-old daughter looking after her moderately disabled mother gives one example:

The most difficult time was the first month after she was discharged from hospital. I was under a lot of pressure. This was because I did not have any of those devices to assist me that were available in the hospital. I wish there had been some professionals to give me advice and assurance. But nobody was available to give me a hand. All of my other brothers and sisters had to go to work. They could only provide financial support, but not...
It is much better now. So I was always the one in the family to deal with different things before. If I am capable of doing it, I am willing to do it without asking for any return. (Participant # 3)

A 67-year-old man with heart disease and a pacemaker looking after his severely disabled wife gives another example:

It is related to something that people in the society should realize—that there was nobody available to teach me how to care for her... I did not have any money and I did not have any information about where to receive help and what resources were available in the community at that time. Nobody informed me. I preferred to save some money from food and hired a homemaker to come and help me to clean the windows since I cannot reach up that high with my heart condition. (Participant # 4)

A 72-year-old woman looking after her mildly disabled husband gives another example:

I had gone through those difficult times when he was discharged home from hospital, but I don’t feel comfortable making recommendations to others about caregiving... It depends on how the carer handles the problem. You can’t simply learn from other people’s experience! This kind of thing cannot be taught. Everyone has their own way of thinking so they have their own way of doing things. It might not be the same way as I care for my husband. Therefore, I would not talk to or teach other families of people with stroke. (Participants # 2)

In this study, the spouses and adult children of caregivers primarily provided kinship support for their spouses and older parents with stroke. They also provided economic and/or practical support to their stroke relatives with physical disabilities. Family caregivers in this study were asked if they thought that any extra kinds of support or services might have made any difference to the patient at home. Older female spousal caregivers thought that such services could not have really made any difference. Although older spouses particularly described themselves as overwhelmed by problems such as sleep deprivation or dealing with the difficult behaviour of the patient or being unable to physically cope with lifting, they refused to seek help within the family and other community services. It was found that the family caregivers in this study believed that those problems are difficult to support by services and they were their own problems, which should not be shared with others. It has been shown that older female caregivers in this study felt isolated and ashamed of their feelings of inadequacy. These findings were congruent with the Chinese culture and belief system (Bond, 1993; Yang, 1992).

In addition to the support provided by family members, some of the caregivers reported resorting to paid support when they had no other alternative. The orders of needs for individual family caregivers in this study were different. Some families were critical of respite care or short-term care while other families were not. It is problematic to arrange for appropriate care when people need intensive personal attention. Care assistants came either very late in the morning or very early in the evening to assist the patient in getting up or going to bed. The findings make it clear that when this kind of support was not available at appropriate times, this was itself another source of stress. Many of the family caregivers concerned also felt that they had been pressured into moving their relatives out of the hospital too early.

**Theme 4: Maintaining a balance between caregiving needs and one’s own needs**

Caregivers complained that they had difficulties managing tasks and maintaining a normal life. Caregiving tasks include ensuring a safe environment, checking the patient’s blood pressure, checking to see that the patient is well covered at night time and showing love and providing emotional support. The family caregivers in this study also stated that they had their own health problems and indicated that it was important to exercise and have time for oneself to maintain a healthy lifestyle in
order to be able to keep performing their caregiving tasks. But it was difficult to maintain a balance. The following remarks are illustrative:

A 55-year-old woman looking after her husband with severe disability and Parkinson’s Disease gives one example:

I would go by myself. I needed to have my own space. Although I cared for my husband, I told my niece that I needed to have some time for myself. I needed to go out and relax because he was emotional and so was I, when I was so tired at one point. I told them that I needed to go to the Cultural Centre. I asked them to come and take care of him for me. When I felt unhappy, I would have a buffet. I would go out for afternoon tea and I did not stay home. I would wheel my husband to the Mall or to go to the fast food store for a change. I would feel better after. If I were unable to go out, I would sing with my Walkman in the house. I dealt with this problem okay. (Participant # 5)

A 65-year-old man looking after his severely disabled wife with epilepsy gives another example:

I have lots of worries. For example, my students were not very cooperative and I did have some teaching problems. I tried to put aside these worries since my wife’s illness is always on my mind. I was panicking about the recurrence of her seizures. The most important thing is that I must have good health. I ought to be very careful about my life. I trust we can’t resist fate ... What I can do is to try to relax whenever possible and not give myself too much pressure. (Participant # 8)

A 77-year-old woman looking after her husband with severe disability gives another example:

I am not healthy enough. I have had heart disease for over five years. I go for regular check-ups at Eastern Hospital. I always take medication. My heart valve has enlarged.

The doctor said that it couldn’t be made smaller anymore and taking medication could be the only way to prevent its further enlargement. I often have low blood pressure; sometimes my diastolic pressure is only about 50-something, and the systolic pressure is only about 80-something. I always have low blood pressure. I always go for check-ups... Sometimes it is hard for me when I need to grip him. I feel like something is blocking my breathing. (Participant # 15)

The caregiver’s own health problems could make it difficult for him/her to continue providing care at home. Six of the family caregivers in this study (three husbands and three wives), whose relatives needed physical help in getting into a bath or with getting out of bed or with dressing, reported being unable to continue providing care without extra help because of serious back problems. Some of them also experienced problems with the dependent spouses becoming doubly incontinent, although they never gave this as a reason for giving up on providing care at home. The older caregiver spouses in this study reported having more serious health problems than the younger caregivers. The older family caregivers in this study reported suffering from high blood pressure and insomnia. One of the husbands, for example, felt unable to push his wife’s wheelchair following his by-pass heart surgery. Family caregivers in this study talked about experiencing physical and emotional pressure that they considered were stress-induced. These included: difficulty sleeping, weight loss, chest pains, elevated blood pressure, and anxiety.

DISCUSSION

This study found that the community support services for family caregivers of elderly stroke survivors in the study are desperately insufficient, which has not been adequately studied (Lee, 2001; Mackenzie, Holroyd, & Lui, 1998). Consequently, either the elderly patient or the family members become victims. In this study, wives (older caregivers) in the Chinese community who cared for patients were far less likely to seek help than...
daughters (younger caregivers). Wives (older caregivers) in this study had a particularly heavy burden of care and yet were the least likely to receive support services. Possibly the spousal caregivers in this study believed their roles were to care for their stroke-spouse and not to expect others to help. One of the most stressful events is generally acknowledged to be the time when the patient is discharged from hospital to go home, without any support being given by health care providers in the community. Such a move is likely to be traumatic for both the caregiver and the stroke elderly, as the caregivers are not knowledgeable about caregiving. It was during this period that the caregiver’s health was most vulnerable. Some of the family caregivers in this study had reached the point of being unable to cope either physically or emotionally with their relatives’ needs for continual support, and therefore institutionalized their relatives as a support alternative. This result is consistent with the findings of previous studies that have indicated family caregivers found various unmet needs in caregiving (Archbold et al., 1990; Jackson & Cleary, 1995; Killeen, 1989). Therefore, it is particularly important that community health nurses in Hong Kong invite family caregivers of people with stroke, especially older Chinese family caregivers, as their partners to plan and develop effective and appropriate hospital discharge programmes together with health authorities and community health services.

CONCLUSION

Community Nursing Services in Hong Kong are particularly suited to assist family caregivers to cope with new demands during the initial recovery period for their relative with stroke. Acknowledging the pressures placed upon the caregiver, directing the family to supportive programs and identifying special needs of the family caregiver should all be included in the initial discharge care plan. Based on their experiences, Chinese family caregivers in this study voiced out their concerns and shared their insights on caregiving. Implications for further practice suggest establishing community training programmes and support groups for family caregivers. Further joint work between community nurses and researchers needs to be done to evaluate the effectiveness of this type of programme in meeting family caregiver’s needs in Hong Kong.

REFERENCES


**照顾中风老年家人：香港华人家庭关顾者的经验**

这篇论文是采用质性设计方法，去了解香港华人家庭关顾者个人经验的初步报告。本研究员深入访问十五个家庭关顾者在照顾中风老年家人时关顾的经验，探讨并分析关顾者在管理关顾职务的需要。质性研究方式的好处是能产生丰富的资料，特别是有关家庭关顾者的个人经验分析，以了解家庭关顾者在照顾中的程序和特质，亦有助探讨关顾者个人及家庭成员在压力情况下关顾的动机、策略及过程。

本研究员采用质性设计「定期比较方法」的步骤去探索香港华人家庭关顾者个人经验。研究员定期分析研究的资料，并将关顾者职务上自然出现的不同现象及经验分类，研究结果显示香港华人家庭关顾者在职务上，深深中国传统文化及家庭的传统的影响。研究结果显示家庭关顾者有不同层面的需要，这些需要亦随关顾过程中不同的阶段的需要及身体状况，出现变化。研究员并将关顾职务的成果分为三十八类，这类分类，与关顾者与关顾者相关的。本研究员再将这三十八类的关顾职务，概括为四个重要的主题：一、学习适应新的角色；二、管理家人的病情；三、评估家人及社区支援的资源；四、平衡关顾者与受关顾者的需要。本研究取得的结果，有助设计华人家庭关顾者职务测量表的评估工具，协助专业护理人员评估华人家庭关顾者在职务上的需要，而提供适当的协助。