

## Care for the Family in Palliative Care

Dr. Tse Man Wah, Doris,

Chief of Service, Department of Medicine & Geriatrics / ICU, Caritas Medical Centre.

Correspondence: mwtse@ha.org.hk

### Introduction

A cancer patient, once being diagnosed as such, may undergo various crisis moments along the trajectory of his/her illness. The initial diagnosis of cancer is one, and the diagnosis of relapse is another. Cancer treatment, be it of curative or palliative intent, can be a demanding period for the patient and family both physically and emotionally. As the disease advances, disabilities and symptom progression are major sources of sufferings. Finally, when facing death, anticipatory grief can be overwhelming.

Throughout this journey, the family members, being with the patient, are also facing their own stresses and changing roles which may be directly or indirectly related to the patient's illness. The family also to undergo the grief process before and after patient's death. The cancer illness, therefore, is a family matter.<sup>1,2</sup>

In palliative care, we serve our patient and the family as a unit, and we extend the care to the family in grief after patient's death. Being the informal caregivers, family members are crucial in maintaining the well being of the patient at home. The well being of the patient in turn affects that of the caregivers. When patient is not communicable or unable to speak for himself or herself, the family will act as the proxy or surrogate for reporting symptoms and making medical decisions.

A family member, therefore, is a caregiver and a care receiver. They have multiple roles, which are potentially conflicting. They can be facilitator or a barrier during the care process.

### The task of caregiving

An informal caregiver faces many potential tasks when caring for an advanced cancer patient at home.

The family caregiver has to provide care directed towards the patient. Examples include administration of drugs, wound care and dressings, toileting, bathing, laundry, preparing food, seeking alternative medicine, assistance with mobility, and providing emotional support to patient.

At the same time, the caregivers have to work on themselves, including dealing and coping with own emotions, resolving uncertainty, struggling with

acceptance of illness and compensating for personal time.

Lastly, the caregiver also has to perform interpersonal and other social tasks such as interaction with medical professionals, meeting needs of other family members, interaction with other relatives, managing finance and others.

### The difficulties and the stress of caregiving

Even if given the same tasks, however, the stress perceived or imposed on the caregivers also varies with multiple factors. Results from a few local studies shed light on the difficulties and the stresses of the informal caregivers of patients with advanced cancer in Hong Kong.

In one cross sectional survey<sup>3</sup>, the burden of 26 informal caregivers were assessed by two questionnaires: (1) Rutter's Malaise Inventory with 24 items to assess physical and psychological symptoms of caregiver (2) Caregiver Tasks Inventory with 45 caregiver tasks. Results showed that caregivers experienced significantly more psychological distress 0.36 (SD=0.22) than physical distress 0.24 (SD=0.22). The three most commonly identified stress items were all psychological, including feeling tired most of the time (62%), often get worried about things (59%), and easily upset or irritated (55%). Caregiver's education level was inversely related to their psychological symptoms ( $r=-0.41$ ,  $p<0.05$ ) and the total stress symptoms ( $r=-0.47$ ,  $p<0.05$ ). Caregiver's perception of difficulty in performing tasks was positively related to their total stress symptoms ( $p<0.001$ ).

In another local exploratory study on 21 informal caregivers of advanced cancer patients at home<sup>4</sup>, 20 caregivers perceived difficulties in caring. Four major difficulties were reported, including (1) relationship with the patient (11/21) (2) emotional reactions to caring (9/21) (3) physical demands in caregiving (10/21) (4) restriction in social life (16/21). Twenty caregivers perceived home care support from the nurses useful (> support from family or friends,  $p=0.003$ ), especially in the area of information giving, emotional support and skill training.

The tasks of caring and the stresses also vary with the trajectory of the cancer illness and the status of the patient. In one overseas study on

family caregiver burden<sup>5</sup>, breast cancer patients and their principle caregivers were followed longitudinally. The study began with 84 pairs of patients and caregivers. At the end of the study, 24 pairs were able to complete analysis. Assessment tools or questionnaires to be completed at different time intervals include: Karnofsky Performance Status, SF-36, Hospital Anxiety Depression Scale (HADS), Zarit Burden Inventory, FAMCARE and MOS Social Support Inventory. At the start of the palliative phase (n=84 pairs), patients had significantly lower physical summary scores in SF36 than the caregivers [mean difference (95% CI) 16.2 (-20.0 to 13.3), p<0.001], whereas there was no difference in the mental summary scores [mean difference (95% CI) 0.5 (-2.5 to 3.1), p=0.8]. The anxiety and the depression score as measured by the HADS, also showed significant correlation between the patients and the caregivers.

At the start of the palliative phase, predictors of caregivers' anxiety included caregiver burden, patient's anxiety and patient's physical functioning; while the predictors of caregivers' depression included caregiver burden and patient's emotional support. Towards the terminal phase, 24 pairs were available for comparison of caregiver burden with the initial palliative phase. There was a significant increase in depression score (HADS) of the caregivers in the terminal phase [mean difference (95% CI) -2.9 (-4.6 to -1.2), p= 0.002]. There was also a significant increase in the caregiver burden [mean difference (95% CI) -6.8 (-12.7 to -0.9), p= 0.02]. Their satisfaction with care, however, remained the same.

### **Vulnerability of family caregivers**

From the above, one can appreciate that caregivers are at risk of adverse physical and emotional outcomes during the caring process. Informal caregivers can suffer from fatigue, inadequate sleep and rest, lack of exercise, and poor nutrition. Emotionally, they may have anxiety, depressive mood, and worries about the burden and the uncertainty of future.

The well being of the patient as perceived by the caregiver also has an impact on that of the caregiver. Unrelieved symptoms in patients have been found to be one such factor. In one study of 152 caregivers of cancer patients who died<sup>6</sup>, the level of caregiver depressive symptoms was related to number of patient's symptoms. Caregivers caring for patients with more physical symptoms reported more disruption in schedule.

In another questionnaire survey on 506 widows whose husband died of prostatic cancer<sup>7</sup>, the psychological distress of widows was found to

be related to patient's unrelieved mental symptoms. Widows who perceived patient to be anxious in last 3 months of life were associated with increased risk of depression [RR 2.5 (1.4 – 4.3)] and anxiety [RR 3.4 (1.4 – 8.2)].

### **Family of advanced cancer patient: a duty to care?**

One may presume that the family members have the duty and the wish to care for the sick patient, even though the process is difficult and stressful. In clinical palliative care practice, we have ample experiences that this need not be the case.

In the local study that is being mentioned above<sup>4</sup>, the 21 caregivers took up the role of caregiving for the following reasons: (1) duty to care in 16 out of 21 (2) love & affection in 12 out of 21 (3) no alternative in 6 out of 21 (4) family expectation in 4 out of 21 (5) piety in 1 out of 21.

The role of the family in the context of a member suffering from cancer is also greatly affected by the ambient culture and the social milieu. Traditionally, in the Chinese culture, children should take care of their parents as an act of filial piety. The family functions as a unit, and the family interest is often above one's own interest. The care duty is the obligation of the eldest son, though female members are often considered as "natural" caregivers e.g. daughters.<sup>8</sup>

However, in the contemporary society of Hong Kong, there is a trend for smaller households. There is also a rising labour force from women. Caregivers are also expected to be self sufficient, independent and to contribute to society. The personal goal of the caregiver may be in conflict with that of the family, and intrusion into time, space, life style may not be as well tolerated.<sup>9</sup>

The modification of the disease pattern is also affecting the caregiving process. There is a shift of medical care from hospital to the community. Patients' last months may be modified by advances in tumour targeted treatment and the coexistence of other chronic debilitating illnesses.

### **Caregivers as barriers**

Family members can be good partners in patient care. However, due to various reasons, family members can also be barriers too. The following 2 studies highlighted the barriers in pain control at home related to the family members.

In one Taiwan study<sup>10</sup>, 80 pairs of patients & caregivers were assessed by Barrier Questionnaire-Taiwan (BQ-T). Results showed that the main concern of the caregivers include the need

to administer drugs on a PRN basis, the need to monitor side effects of drugs, and the perception that pain was indicative of disease progression. The older and the less educated caregivers had higher BQ-T scores and the BQ-T score was associated with reluctance to administer drugs by caregiver. The BQ-T score of patient also correlated with that of the caregiver.

Similar results were found in a Caucasian study.<sup>11</sup> The Barrier Questionnaire (BQ) was administered to 37 caregivers. The older & less educated caregivers believed that reporting pain would distract doctor from 'curing' the disease, and they had higher BQ scores. Those who reported pain not a problem had greater concerns about tolerance and more likely to believe that good patients did not complain of pain

### Supporting the family in palliative care

Although care of the family is an integral part of palliative care, there is a relative lack of structured approach in the provision of care. There are also relatively few studies on the efficacy of family support to these families. In a systematic review on "relatives in end-of-life care"<sup>12</sup>, a total of 94 studies were found, 59 were qualitative, and 55 were quantitative. Eight studies were from Asia, among which five studies were conducted in Hong Kong.

In palliative care, care for the family is directed towards the following goals: (1) meeting the needs of the family (2) minimize caregiver's distress (3) improving the well being outcome of caregivers (4) empower family to maintain patient's comfort. How far can we achieve this? What is the effective approach? We do not have good answers to these questions.

The following discussion is on an empirical approach to supporting families in palliative care, with reference to the Stress and Coping Theory. (Lazarus & Folkman)<sup>13</sup>

### Stress and Coping<sup>13</sup>

People when facing stressors, will have their own appraisals of the stressor and the situation. These stressors can be perceived as a challenge or a threat, and the emotional outcome of the one facing the stressor is affected by their appraisals and the effectiveness of their coping strategies. Generally speaking, coping serves two broad functions, in terms of problem focused coping and emotional coping. The former is to modify the stressor if possible, and the latter to modify how one feels about the stressor.

During the process of appraisal, the informal caregivers will assess whether resources are adequate to meet the demands. Resources can be from two sources (1) the inner resource of the caregiver, which is the strength inside the person that can be drawn up in stress (2) the outer resources, which refer to things like income, education, knowledge, social status and social support.

Various coping patterns have been identified, including (1) confrontation e.g. fight for what is desired (2) distancing e.g. refuse to think about it (3) self controlling e.g. keep the feelings to oneself (4) seeking social support e.g. talk to someone helpful (5) accepting responsibilities e.g. promise to do better (6) escape-avoidance e.g. sleep and eat more (7) planful problem solving e.g. make an action plan to follow (8) positive re-appraisal e.g. feeling renewed and rediscovered life meaning. Although there may be common patterns in an individual, people tend to use most ways of coping depending on the degree of the stressor and the situation. Personality, past life experiences, and in this context, past medical experiences may also affect how family members cope with the situation. What works for one situation may not work for the other, and therefore there is no good or bad coping, but instead, effective or ineffective coping.

The outcome of the coping process i.e. positive or negative well being of the caregiver depends on their appraisal. Positive experiences may reinforce effective coping methods, sustaining the caring process. (Fig. 1)

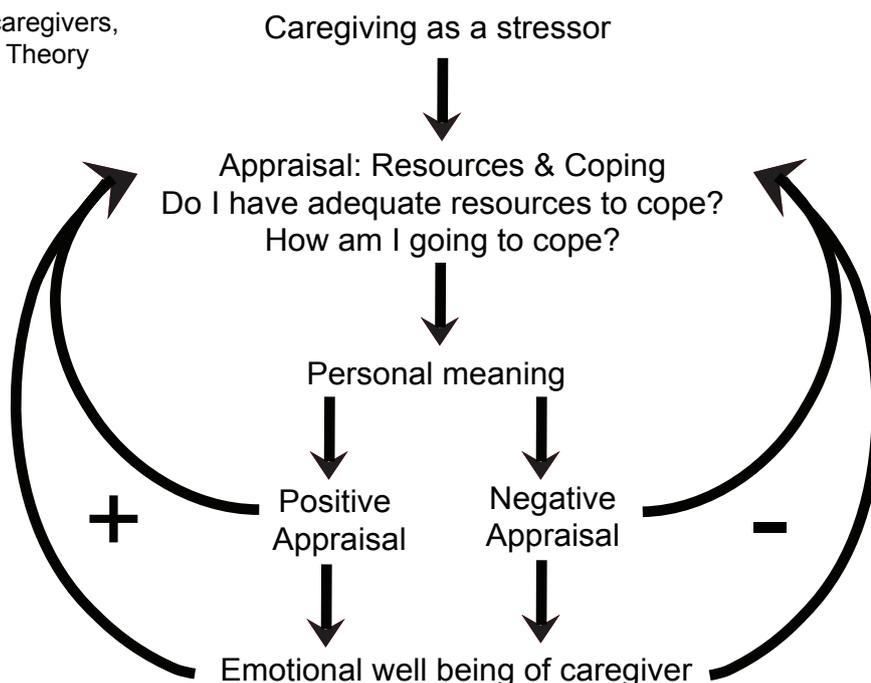
### Empirical clinical framework in supporting family in palliative care

With this background model in mind, I shall continue my discussion on an empirical clinical framework in supporting the family in palliative care, which consists of (1) modification of the stressors (2) enhance resources and coping (3) reflections and transcendence. (Table 1)

Modification of the stressors means optimizing patient's condition for care including minimizing symptoms and maximizing function. Uncertainties should be avoided by good communication and realistic discharge planning.

Enhance resources and coping can be directed towards tangible support, practical problem solving, information giving and skill training. All these have to be tailored. For example, although information giving is generally regarded as important, one will agree that massive, non specific information will not be helpful. One study has

Fig. 1 Stress and coping in family caregivers, based on Stress and Coping Theory (Lazarus & Folkman)



identified some specific areas of information that were regarded as important to caregivers, including the medical aspect and how to anticipate the course of cancer, how to interpret the emotion of patient towards the caregiver, and how to interpret the impact of illness on school aged children etc. Psychological support can be given in the form of mental respite e.g. allow time for performing another activity, enhancing stress management, or even formal psychological intervention.

Although stressful, many family members sustain their caring process as they find meaning in the caring process. Such meanings are personal, but also affected by the cultural and the religious context. Spiritual care, as an integral part of palliative care, helps patients and families to transcend beyond their sufferings. Such process can be facilitated by means such as cognitive process, narration, legacy for the family.

**Assessment? Evaluation? Effectiveness?**

However, each family is different, and there is a need to customize the needs and therefore the care provided. Such “assessment” and identification of needs are part of our daily clinical practice, but there are still unresolved issues in this area.

Getting to know the family is what we palliative care workers regarded as an important part of patient care. In general, there is lack of a structured approach in assessing the family in clinical practice. Table 2 contains the list of potential useful information of the family that can be helpful in formulating the supporting strategy. This should not

Table 1: Supporting the family: an empirical framework

- Modify Stressor
  - Optimize symptom control
  - Maximize functional capacity
  - Clearly communicated drug regimen
  - Anticipatory, realistic discharge planning
- Enhance resources & coping
  - Information
  - Skill training
  - Finance
  - Equipment, home modification
  - Other tangible support
  - Respite: physical or mental pause
  - Stress management
  - Emotional support
  - Psychological intervention
- Transcendence
  - Spirituality
  - Cognitive process of meaning in illness
  - Means: legacy, narration
  - Cultural context
  - Religious context

represent an obligatory list to go through, as differentiating the need to know from intrusion into the privacy of individual family members may be difficult.

Establishment of a structured family support program and its evaluation has been reported. In the Family Caregiver Education Program<sup>14</sup>, a nurse and a social worker served as the trainer for the

Table 2: Assessing a family in palliative care

- A family tree
- Significant others
  - Blood related or non-blood related
  - Overseas or local
  - Legal or non-franchised
- Kinship
  - Direct care giving
  - Indirect care giving e.g. finance
- Family culture & decision making
  - Key decision maker(s)
  - Dominant values
- Communication channels
  - Persons
  - Network of dissemination
- Key family functional parameters
  - Cohesiveness
  - Conflict: presence and ability to resolve
  - Expressiveness
- Resources & coping
  - Finance
  - Household work: maid, home helper
  - Social network: friends, church mates
  - Advocacy: social worker, community leader
  - Adaptive & maladaptive coping patterns
  - Ability to mobilise resources (vs possession)
- Identify family at risk
  - Florid physical and psychological symptoms in caregiver
  - Poor social support & education level
  - Poor family functional parameters as above
  - Maladaptive coping pattern: drug addiction, alcohol
  - Psychiatric illness
  - Multiple or consecutive losses

family caregivers. They underwent one day intensive training in family support and also taught to identify family at risk. Family caregivers were trained in groups of 8 to 15. The 6 hour curriculum was delivered in 2 sessions, with focus on symptom management, technical competence, medication administration, stress reduction, depression, managing own health and bereavement. A total of 187 caregivers were evaluated before the program and at 4 months after training by the Caregivers Reactions Inventory (CRI) and the Caregiver Demand Scale (CDS). Results showed that there was significant improvement in: health suffered from caregiving, well informed about caregiving, comfort in caregiving and confidence in caregiving.

In one RCT on the coping skills intervention with family caregivers in palliative care<sup>15</sup>, caregivers were randomised to 3 groups: standard palliative care (n=109 pairs); standard palliative care and 3 supportive visits (n=109 pairs); standard palliative care and 3 supportive visits and teaching on coping skills (n=111 pairs). Results showed that the group with coping skill intervention had better QOL

(p=0.03), less burden of patient symptoms (p<0.001) and less caregiver task burden (p=0.038) as compared with the other 2 groups.

**Conclusion**

Caring for families in palliative care is important. More knowledge and findings in application of family assessment in the clinical setting, monitoring of family well being, exploration of their needs, assessing effectiveness of family support are relevant to focusing and improving care for the family in palliative care.

**Reference**

1. Liao S & Arnold RM. Caring for caregivers: The essence of palliative care. *J Pall Med* 2006;9(5): 1172-4.
2. Hebert RS, Schulz R. Palliative care review: Caregiving at end-of-life. *J Pall Med* 2006;9: 1174-87.
3. Chan C & Chang A. Stress associated with tasks for family caregivers of patients with cancer in Hong Kong. *Canc Nurs* 1999;22(4):260-5.
4. Yuen Loke A, Liu F, Szeto Y. The difficulties faced by informal caregivers of patients with terminal cancer in Hong Kong and the available social support. *Canc Nurs* 2003;26(4): 276-283.
5. Grunfield E et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ* 2004;170(12): 1795-1801.
6. Given B. Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum* 2004;31(6):1105-17.
7. Valdimarsdotti U, Helgason AR, Furst CJ et al. The unrecognized cost of cancer patients' unrelieved symptoms: a national wide follow up of their surviving partners. *Br J Cancer* 2002;86:1540-45.
8. Holroyd E, Machenzie A. A review of the historical and social process contributing to care and caregiving in Chinese families. *J Adv Nursing* 1995;22(3):473-479.
9. Holroyd E. Provision of Nursing Care for HK Families: Future Implication. *The Hong Kong Nursing Journal* 1993;62(6):23-26.
10. Lin CC. et al. Identifying attitudinal barriers to family management of cancer pain in palliative care in Taiwan *Pall Med* 2000;14(6):463-70.
11. Berry PE & Ward SE. Barriers to pain management in hospice: a study of family caregivers. *Hospice Journal* 1995;10(4):19-33.
12. Andershed B. Relatives in EOL care – part 1: a systematic review of the literature the 5 last years, January 1999 – February 2004. *Journal of Clinical Nursing* 2006;15:1158-69.
13. Lazarus RS, Folkman S. *Stress, Appraisal and Coping*. New York, Springer, 1984.
14. Prasacreta J, Barg F, Nuamah I et al. Participant characteristics before and 4 months after attendance at a family caregiver education program. *Canc Nurs* 2000;23(4):295-303.
15. McMillan SC et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized control trial. *Cancer* 2006;106(1): 214-22.