

Caregiving – A Bittersweet Experience Dr Bobo Lau, Senior Training Officer

Taking care of a loved one who is suffering from a terminal illness is never easy. Not only are the chores of caregiving time-consuming, demanding, and exhausting, caregivers also tend to experience a repertoire of negative emotions. Anger, frustration, depression, helplessness, sadness, anxiety, agitation, loneliness, isolation and more are emotions commonly experienced by caregivers. A Canadian study found that 40-60% of caregivers of patients with advanced cancer experienced significant psychological distress, compared to just 19% among the general public.¹ Another study, conducted in Australia, reported that as many as 32% and 12% of caregivers of palliative care patients demonstrate clinical levels of anxiety and depression, respectively.² Middle-aged caregivers showed a greater sense of abandonment and more depressive symptoms than caregivers of other age groups.³ Caregivers who were women, adult children, or who took care of patients with greater symptom burden, also experienced an elevated sense of abandonment. In fact, we probably do not need empirical research to inform us: Familial caregiving for end-of-life patient is emotionally taxing.

However, increasingly, researchers have found that negative emotions alone do not fully depict the emotional experiences of caregivers. For example, imagine a woman who has been married to a loving man who suffers from a type of cancer that is difficult to treat, for over 30 years. Even though her care-taking tasks—from feeding to supporting him in all his pains—can be very demanding, “quitting” is not really an option for her. Behind the suffering of the caregiver are the memories, shared experiences, responsibilities, identity, and reciprocity that is derivative of a long-established relationship and that is integral to their relationship.

Although the care-taking role may look distressing to an outsider, in order to fully support the care-giver we need to understand their courage to take on this journey with their loved one, and appreciate the strength of their relationship. Sometimes, as friends and family members of the caregiver, we may be tempted to feel sorry for him/her and insist that they “need a break”. Yet, our appreciation on the relational strength between the caregiver and the patient

¹ Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vezina, L. (2006). Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine*, 9, 912-921.

² Gough, K., & Hudson, P. (2009). Psychometric properties of the Hospital Anxiety and Depression Scale in family caregivers of palliative care patients. *Journal of Pain & Symptom Management*, 37, 797-806.

³ Given, B., Wyatt, G., Given, C., Gift, A., Sherwood, P., DeVoss, D., & Rahbar, M. (2005). Burden and depression among caregivers of patients with cancer at the end-of-life. *Oncology Nursing Forum*, 31, 1105-1117.

will enable us to support the family in a more sensitive manner.

When we are faced with death, we are essentially coping with the anticipatory loss of a person, a relationship, an identity, and many more, which can be extremely painful. For many families, confronted by the finitude of time, caring for the end-of-life patient provides an opportunity for mending broken relationships, seeking (or offering) forgiveness, reuniting family members, showing gratitude, and expressing love. The suffering of the caregiver will become more meaningful has his/her caretaking work been conducive to reconciliation of difficult relationships or strengthening of existing ties.

Not only does the growth in relational strength lighten up the experience of caregiving, caregivers may also experience transformative growth when providing care to their loved ones. Research has shown that many bereaved caregivers recalled the caregiving experience as a meaningful event in their life that leads to greater self-acceptance, enhanced sense of mastery, and reprioritization about his/her life.⁴ The time spent in accompanying, helping, and bringing happiness to the patient can offer great meaning, satisfaction, and feelings of reward to the caregiver.^{5,6}

Conclusively, an important role for supporters and professionals is to facilitate the caregiver to experience perceived rewards or “gains” from the caregiving role. We may help caregivers to rediscover the meaning of their pursuit, savour the uplifting moments in their caregiving tasks, and remind them of how big a difference they are making to the life of their loved ones.

⁴ Kang, J., Dong, W. S., Choi, J. E., Sanjo, M., Yoon, S. J., Kim, H. K., . . . ,Yoon, W. H. (2011). Factors associated with positive consequences of serving as a family caregiver for a terminal cancer patient. *Psycho-oncology*, 22, 564-571.

⁵ Henriksson, A., Carlander, I., & Arestedt, K. (2015). Feelings of rewards among family caregivers during ongoing palliative care. *Palliative and Supportive Care*, 13, 1509-1517.

⁶ Salmon, J. R., Kwak, J., Acquaviva, K. D., Brandt, K., & Egan, K. A. (2005). Transformative aspects of caregiving at life's end. *Journal of Pain and Symptom Management*, 29, 121-129.