

## **Cancer Family Caregivers: What are Their Needs, Burden of Care and Quality of Life over the Course of a Cancer Illness?**

Cancer is on the rise in Singapore, with an increase from 11,758 cases in 2011 to 14,148 cases in 2015. The chronicity of cancer has shifted care to the home, with family members often being the main care providers for cancer patients. However, the impact of a cancer diagnosis, treatment and sequelae on family caregivers is often overlooked even though it significantly affects the integrity and stability of the family unit. There is a demand to uncover the unmet needs of family caregivers of cancer patients across their care recipients' illness trajectory, so as to develop programs to establish support and help for family caregivers. In this interview, **Dr Rathi Mahendran**, an Associate Professor from NUS, shares about her recent research addressing the knowledge gap of caregivers' unmet needs and stress, burden and quality of life.

**Q: How did you get interested in studying the unmet needs among cancer family caregivers?**

**A:** While I have met many caregivers who derived personal fulfilment and satisfaction in helping their loved ones, they were also facing significant stress. The caregiving situations they were in were sometimes persistent and long-term, and sometimes unpredictable and uncontrollable. Yet many had little support as there has been limited attention to caregivers' needs in Singapore. I felt it was important to identify their unmet needs so that they could be adequately supported in their caregiving role.

**Q: Can you briefly introduce your study and what are the major research findings?**

**A:** This study examined cancer family caregivers unmet needs by using a questionnaire called the Needs Assessment of Family Caregivers – Cancer (NAFC-C). Data from more than 400 participants showed that unmet needs were present in all four domains studied: Medical, Psychosocial, Daily Activity and Financial needs. Of these domains, Medical Unmet Needs of caregivers were highest and this was consistent throughout the entire duration of treatment. The early treatment phase, (initial 6 months), was associated with the highest burden of care and lowest quality of life for caregivers.

**Q: What do you propose for future programs to support and help cancer family caregivers?**

**A:** It would be important to focus support for caregivers in the early treatment phase. More importantly, each individual caregivers' needs, stress and burden should be identified for a more targeted approach. Future programs could: (1) address caregiver's knowledge gaps and provide education about the illness, (2) provide skills training in symptom management and care, (3) educate on relaxation measures to de-stress and (4) provide group sessions to build resilience and support.

**Q: Do you have any advice for cancer family caregivers?**

**A:** Caregivers need to realise that the cancer journey may be long and arduous. They should learn to accept and respect their care recipient's wishes and support them in their decisions. There may be 'good days' when their loved one feels better, and they can find strength and solace in those days in preparation for the 'difficult days'. Caregivers need to recognise their own needs and take care of themselves. This includes taking breaks from their caregiving roles to re-charge, maintaining a healthy diet and exercise and rallying support from others when required.

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**Researcher portfolio**

This study was completed by the team led by Dr Rathi Mahendran, who is an Associate Professor from National University of Singapore. Her interests are in psychopharmacology and medical education. She also provides psychiatric care for ambulatory patients at the National University Cancer Institute, Singapore (NCIS).

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