Abstract

Cancer caregiving is emerging as one of the most daunting demands of our time. Caregiving is understood as an inherent function when a family member is ill, but due to increased prevalence of cancer, breakdown of traditional familial support systems and the managed care model, caregiving has become a significant developmental or life-course challenge for many. The understanding of what makes caregivers cope well is become increasingly necessary because quality care of a cancer patient greatly depends on the caregiver. The current study aimed to understand the cancer caregiving experience in the Indian context. The study was carried out in two phases. In the first phase, a sample of one hundred and ninety family caregivers of cancer patients was selected using the purposive sampling technique from hospitals in Bangalore. These caregivers participated in descriptive survey using an ex-post facto design which assessed their levels of general health, quality of life and coping processes. The General Health Questionnaire, the Caregiver Quality of Life Index- Cancer and the Brief COPE were used in this phase. The Brief COPE was factor analysed to understand the underlying structure of the fourteen subscales in the study setting; a five-factor structure emerged and was used in the current study. The participants also provided their responses to a detailed questionnaire on their socio-demographic status and various factors related to the illness and the consequent caregiving process. The results of the survey indicated that general health and quality of life were significantly associated with each other as well as with the evasive and dysfunctional dimensions of coping. Significant
interrelationships existed between support coping, evaluative coping and active coping as well as between evasive coping and dysfunctional coping. Gender, education, employment, socio-economic strata and a religious or spiritual orientation were related to health and quality of life; these variables also affected the degree to which caregivers used the different coping strategies studied. Poorer self-reported health was also related to worse caregiving outcomes, while marital status and family type had no such effect. Caregivers looking after male, low-literacy and unemployed care-recipients reported poorer caregiving outcomes. Those who provided substantially long hours of care and lacked medical coverage also reported poorer health and quality of life as well as a propensity to use dysfunctional coping strategies. The second part of the study involved ascertaining the feasibility of an intervention combining psycho-education and emotional support to improve general health. A single-subject design of the ABA (withdrawal) subtype was utilized for this phase. Of the sample of five caregivers, four completed the whole intervention with three caregivers reflecting statistically significant reductions in psychological distress as assessed by the General Health Questionnaire. Effect sizes of .84 and .90 were calculated for two of the intervention participants. The results of the study underscore the need to view cancer as a family illness. There is a vital need to understand the impact of cancer on the caregiver’s overall health and quality of life along with assessing the personal and social resources they possess to cope. Armed with this knowledge, assessment and interventions focused on emotional support, information relevant to symptom management and a general sense of family inclusivity in cancer care may be contemplated. Such an approach has to be integrated into mainstream cancer care, rather than being provided on a piecemeal or optional basis. The role of informed health psychologists and psycho-social oncologists is integral in this
context. Some findings of the study, such as the socio-cultural nuances to caregiving in the Indian setting, the potential stage-wise progression of coping strategies among caregivers and the possibility of designing new intervention modules which are both short and effective warrant further study.

*Keywords: Cancer caregiving, health, quality of life, coping, psychosocial oncology, emotional support, single-subject design, two standard-deviation method, psychosocial oncology*