

ABSTRACT

Introduction- Identifying and addressing the psychosocial needs and distress of primary caregivers (PCG) of children and adolescents with cancers (CAAWC) is emerging globally, as a component which should be incorporated into the quality cancer care.

Objective - To describe the psychosocial needs, psychological distress and associated factors among primary caregivers of children and adolescents with cancers at National Cancer Institute (NCI), Maharagama (Apeksha Hospital at present) and to assess the outcome of a psycho-educational intervention to address their emotional and informational needs.

Methods - This study consisted of two phases and phase one had two components.

Phase 01: component 01- Development and validation of an interviewer-administered, needs and knowledge assessment questionnaire (NKAQ) based on the literature and findings of Focus Group Discussions (FGD) conducted among PCG of CAAWC. Judgmental validity of the developed NKAQ was established by a group of experts in relevant fields.

Component 02- A descriptive cross-sectional study was conducted among 180 PCGs of CAAWC who were in post-diagnosis stage of between one-four months duration, attending NCI Maharagama. Study instruments were the NKAQ which contained questions to assess psychosocial needs (47 items) and knowledge on childhood cancer caregiving (32 items) and GHQ-30 for the assessment of the psychological distress. Associations were sought between caregiver-related factors, sick child-related factors and needs, knowledge, and distress by conducting bivariate analysis using chi-square for proportions and further multivariate analysis applying, binary logistic regression model.

Phase 02- A psycho-educational intervention was developed and validated based on the findings of phase one of the study. A quasi experimental study was conducted including 45 participants into each arm, to evaluate the outcome of the developed intervention on caregivers' knowledge and distress. Baseline and post-intervention (in four-week and 12-weeks) assessments were done. Pre-post comparison and comparison among two groups were carried out using the chi-square test for proportions and further analysis, utilizing GHQ score and knowledge score was carried out using the Mann – Whitney U test.

Results- Twenty-two PCGs participated for FGDs and saturation point was reached by the fourth discussion. Themes which could be identified during the analysis of FGDs echoed the

psychosocial needs already known in the literature. In the cross-sectional study, a total of 170 PCGs completed the questionnaire with a response rate of 94%. Among the assessed need items, under seven major need areas, the top five unmet needs identified were, consecutively emotional needs, financial needs, informational needs, practical needs, need of family and social support. All study participants had at least one item of unmet psychosocial needs. Having a lower education level showed a significant association with a higher level of unmet psychosocial needs (OR=4.990; CI=1.96-12.72).

Only 18% of PCGs had a good overall knowledge level on childhood cancer caregiving. Among all the assessed knowledge domains, awareness on the available supportive care services was found to be very poor among the majority of PCGs. Good knowledge was found to be associated with less distress levels of PCGs (OR =2.46; 95% CI= 1.04 – 5.83), higher level of education (OR = 4.14; 95% C I=1.73- 9.93) and employed state (OR=2.52, CI =1.07 -5.93).

Almost all the PCGs were psychologically distressed (97.6 %; CI = 95.3% - 99.9%) during post-diagnosis one-month to four-months period, irrespective of the factors related to the PCG or child's condition. However, being the mother of the sick child showed a statistically significant association (OR = 2.47; 95% CI = 1.06 – 5.820) with distress.

Phase 02-

The developed and piloted Psycho-educational intervention, addressing caregivers' emotional and informational needs was found to be effective in improving knowledge on caregiving ($Z = -5.01$, $p < 0.001$) and reducing distress levels ($Z=-3.48$, $p < 0.001$) among childhood cancer caregivers, in the short term.

Conclusion and recommendation-

Almost all PCGs of CAAWC who were at early stages of diagnosis are highly distressed and having a lot of unmet psychosocial needs.

Interventions such as the piloted Psycho-educational intervention should be implemented to address their emotional and informational needs, improving their preparedness for caregiving.

Keywords: Childhood cancer, Caregivers, Psychological distress, psychosocial needs, Informational needs, Emotional needs, Psychoeducational interventions.