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Primary caregivers of children with cancer, Sri Lanka; A journey through their Psychological distress, Psychosocial needs, and Knowledge on caregiving



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Abstract: Identifying and addressing the psychosocial needs and psychological distress of primary caregivers of children and adolescents with cancers is emerging globally as a component that should be incorporated into quality cancer care. The objective of this study was to describe the psychosocial needs, psychological distress, knowledge of caregiving, and associated factors among the primary caregivers of children and adolescents with cancers attending the leading cancer treatment center in Sri Lanka. A descriptive cross-sectional study was conducted among childhood cancer caregivers in the early post-diagnosis stage using a needs and knowledge assessment questionnaire and General Health Questionnaire-30. Associations were sought between variables by bivariate analysis and further multivariate analysis. Consecutively, emotional needs, financial needs, informational needs, practical needs, and need for family and social support were at the top of the unmet needs list. All study participants had at least one item of unmet psychosocial needs. A lower education level was significantly associated with higher unmet psychosocial needs (OR=4.990; CI=1.96-12.72). Almost all the primary caregivers were psychologically distressed (97.6 %; CI = 95.3% - 99.9%) during the early post-diagnosis period. Only 18% of caregivers had a good overall knowledge of childhood cancer caregiving. Good overall knowledge of childhood cancer caregiving was associated with low distress levels (OR =2.46; 95% CI= 1.04 – 5.83). Almost all primary caregivers of children and adolescents with cancers at the early stages of diagnosis were highly distressed and had multiple unmet psychosocial needs with poor awareness of caregiving.

Keywords: Children, Adolescents, Cancer, Caregivers, Psychological distress, Psychosocial needs, Sri Lanka

1. Introduction

Childhood cancer diagnosis significantly changes the lives of those children and their family members. This may lead to a family crisis, drastically changing the 'normal' routines of family interactions (Panganiban-Corales & Medina, 2011). According to the literature, family caregivers caring for loved ones with cancer are at risk for psychological distress, impaired quality of life, higher levels of burden, burnout, poor health, and increased mortality (Fujinami, 2015; Hinojosa *et al.*, 2012). The provision of cancer care is mainly focused on biomedical treatments of the disease currently, and addressing the patient's and caregiver's psychosocial needs is almost neglected, especially in developing countries. Primarily unmet psychosocial needs manifest as psychological distress in cancer patients and their caregivers. Attending to psychosocial needs has been identified globally as an integral part of quality cancer care (Adler & Page, 2008; Thomas *et al.*, 2001). When we consider childhood cancer, from the outset, the family



caregiver's role is complementary to the health care provider's role in achieving a favorable outcome for the patient. High distress levels in caregivers lead to impairment in providing optimum care for the patient. Furthermore, according to the literature, caregivers with higher knowledge of cancer and cancer caregiving are less distressed (Othman *et al.*, 2011). Therefore, the caregiver's knowledge of caregiving is vital in distress reduction.

When all the above facts are considered, it is essential to identify the primary caregivers' psychosocial needs profile, knowledge of caregiving, and psychological distress levels to identify the existing gaps in service provision. This will facilitate addressing the needs through effective interventions alleviating distress and improving positive outcomes for both caregiver and care recipient.

Specifically, the trajectory of adjustment in primary caregivers of children with cancer and their psychosocial need profile has not been studied locally, and the prevalence of psychological distress and correlates of that have not been assessed in the Sri Lankan setting.

This study was the second component of the first phase of a two-phased research project in identifying and responding to primary caregivers' psychosocial needs, psychological distress and knowledge of caregiving. This component was conducted after a qualitative study as the first component, followed by an interventional study in phase two, and carried out from 2017 to 2019.

2. Methods

2.1 Study setting and participants

A hospital-based-descriptive cross-sectional study was conducted at the National Cancer Institute (NCI), [currently known as Apeksha hospital], which is the premier hospital dedicated to diagnosing, treating, and following up on cancer patients in Sri Lanka. This is the main center with specialized pediatric oncology treatment facilities. Therefore, most pediatric and adolescent cancer patients throughout the country are concentrated in this unit for disease management. Further, the pediatric oncology section of this institution provides services for children and adolescents with cancer up to 18 years through four units (clinics and wards) under four consultant pediatric oncologists. Therefore, primary caregivers (PCG) of children and adolescents with cancers (CAAWC) aged 0- 18 (+11 months), receiving care from NCI Maharagama, were considered the study population.

The PCG was defined as a family member older than 18 years of age, who is most responsible for the day-to-day care, spends a minimum of 35 hours per week on caregiving activities, and is involved in decision-making for the child with cancer. Having a confirmed diagnosis of cancer (confirming through medical records), at least one-month post-diagnosis (to rule out the period of possible acute stress disorders) (Bryant *et al.*, 2011), up to four months of diagnosis (to obtain a more homogenous group of primary caregivers who are almost similar in needs and distress levels) and under active treatment were considered as the inclusion criteria. PCGs suffering from psychiatric disorders (self-reported) except depression, where the diagnosis was made following the onset of the child's condition, were excluded.

The sample size was calculated based on the prevalence of psychological distress and two major psychosocial needs based on the literature, utilizing the "Lwanga and Lemeshow" equation. After considering a 10% non-response rate, a sample size of 180 was taken for the cross-sectional study. Participants were recruited to the study following a rapid screening for eligibility, considering consecutive clinic visits or ward admissions, from each clinic and ward until the required sample size was achieved.

2.2 Study instruments

Two study instruments were used as follows;

General Health Questionnaire -30 (GHQ-30) -GHQ 30 is an excellent and quick screening instrument translated into the Sinhala language and validated for the Sri Lankan population (Abeysena *et al.*, 2014). This has been widely and successfully used in Sri Lankan settings for research and clinical purposes (Kumarapeli *et al.*, 2011; Wijesinghe *et al.*, 2014).

Therefore GHQ 30 was used to assess the prevalence of psychological distress among the PCGs of CAAWC. In GHQ 30, there were four responses for each item, and the respondents were asked to indicate the answer



appropriate to her/him by comparing their current state with their normal state. Items were scored using the binary approach known as "the GHQ score." This approach codes four responses as 0-0-1-1 from left to right. According to the Sinhala version of GHQ 30 validated by *Abeyseena et al.*, the best cut-off value for GHQ 30 to detect psychological morbidity is ≥ 6 , with a sensitivity of 67.5% and a specificity of 80%.

Therefore, this study used six positive answers as a cut-off level for psychological distress.

Need and Knowledge Assessment Questionnaire (NKAQ)- The NKAQ was developed during the first component of phase one of this project based on the findings of focus group discussions conducted among PCGs of CAAWC, discussions with experts, and a literature review. The judgmental validity of the developed questionnaire was established by a group of experts. It contained questions to assess psychosocial needs, knowledge of caregiving, and general information about the caregiver and care recipient. GHQ 30 and NKAQ were translated to Tamil, and judgmental validity was established by a group of experts in relevant fields targeting the caregivers whose mother tongue was Tamil.

2.3 Data collection and analysis

The decision was taken to recruit pre-intern medical officers as data collectors (DC), considering the feasibility of approaching and getting information from the caregivers of inward patients. Two pre-intern medical officers were recruited, including one who was fluent in the Tamil language as data collectors. They were provided two four-hour training sessions on the study objectives and data collection.

Data collection was carried out by the principal investigator (PI), and the two trained DCs daily in the afternoons in the wards and during the morning hours in the pediatric clinics. During the first visit to all four wards, all the available PCGs were screened for eligibility, and from the second visit onward, only the new admissions were screened. An information sheet was provided to the eligible study participants. After clarifying their issues related to the study and obtaining written informed consent, data collection was carried out. It took around 30-45 minutes to complete a questionnaire depending on the response rate. Data were checked for completeness at the end of each day and entered into a database using SPSS 17 statistical software package by a trained data entry operator. Descriptive statistics were conducted to describe the profile of respondents.

According to the conventional cut-off of GHQ-30, the distress level was classified into distressed and non-distressed groups to assess the prevalence of psychological distress among PCGs of CAAWC. For further classification of PCGs to a highly psychologically distressed group, the reported mean score of 17 was considered as the cut-off, with the consensus of experts. After categorizing, selected factors were tested for associations with distress levels of PCGs of CAAWC. Classification of knowledge scores into good and poor knowledge levels was carried out by considering the cut-off mark of 85%. The decision was taken to consider 27 correct answers out of 32 (85%) as the cut-off for good knowledge with expert opinion. The Chi-square test for proportions was used to test the association between selected socio-demographic factors and the knowledge level of PCGs. Concerning the psychosocial need assessment, psychosocial needs were classified as "High need," "Need to some extent," "Minimum need," and "No need."

A need that had been rated as a high need or need to some extent was categorized as a significant need. Perceived support for each need was also assessed, and if a need was rated as significant and if the support was not adequate or no support at all, those needs were considered significantly unmet. The distribution of the level of perceived needs in each need item and the level of support received was analyzed and presented in frequencies and proportions. Psychosocial need items were presented under seven major need areas: Financial needs, Practical needs (including needs related to caring for the sick child on day-to-day basis, sick child's siblings caring, PCG's self-caring), Emotional needs, Informational needs, Need of family and social support, Spiritual needs. A ranking of the top 20 need items was carried out to prioritize the most prevalent psychosocial need areas among PCGs of CAAWC.

In addition, a score was given to each need item as an index of the unmet need. A need item got a score ranging from two to six if the need was unmet. The scores of each need item were amalgamated to assess the severity of overall unmet needs among PCGs of CAAWC. Finally, selected socio-demographic factors of PCGs' were tested for associations with unmet need levels among PCGs by utilizing the Chi-square test for proportions. The



relationship between individual psychosocial need scores, GHQ scores, and Knowledge scores was investigated using Spearman's rank correlations.

The factors considered potentially associated with the dependent variable and variables ($p < 0.2$) in bivariate analysis were combined into a multivariate regression model to identify the significantly associated variables with the dependent variable after controlling for confounding. Dependent variables were psychological distress, knowledge level, and overall unmet psychosocial needs, which were entered into three models separately. Finally, the data were subjected to binary logistic regression using the backward elimination method in SPSS. Adjusted Odds ratio (OR) and Confident Intervals (CI) were presented for the variables, which were found to be associated significantly ($p < 0.05$) according to the findings of Logistic Regression.

2.4 Ethics Approval

Ethical clearance was obtained from the Ethics Review Committee of the Post Graduate Institute of Medicine Colombo, and administrative clearance was obtained from the head of the institution of NCI. The confidentiality of the data was maintained throughout the process.

3. Results and Discussion

3.1 Childhood cancer caregivers' profile

A total of 180 PCGs were invited, and 170 of them participated, resulting in a 94% of response rate. Among the study participants, 79% were Sinhalese, while 13% and 7% were Tamils and Muslims. The majority of the PCGs were females (88%), including mothers (84%) and grandmothers (4%), while a small percentage of PCGs were males (12%). Nearly half of the PCGs belonged to the age group 31-40, with a mean age of 36.

Sri Lanka is divided into nine provinces for administrative purposes. The distribution of the study sample among provinces (Figure 1) revealed that the most significant share was from the Western province ($n=35$, 21%), followed by the Central province ($n=28$, 16.5%). The lowest percentage of PCGs were from the Northern province ($n=2$, 1.2%). The distribution of childhood cancer patients among nine provinces was found to be proportionate to the population distribution of Western (28.7%), Central (12.6%), and Northern (5.2%) provinces in Sri Lanka ([The Department of Census and Statistics, 2012](#)). Though around 60% of PCGs were unemployed, most (78%) had a good educational background. Moreover, around two-fifths of the PCGs ($n= 65$, 38%) had an average monthly family income of more than Rs.40,000. Regarding the living area, 66% of the PCGs lived more than 100 km away from the hospital, adding the burden of traveling a long distance to reach the hospital. Around 70% of them were using the public transport system for traveling to the hospital, irrespective of the child's condition. Furthermore, around one-third of PCGs were utilizing the CCC house, a free accommodation facility located within hospital premises, funded by CCC (Courage, Compassion, Commitment) foundation in between treatment sessions.

The mean family size of the PCGs was five, and a little more than half of the PCGs had nuclear families. Most of the time (in 44% of cases), the family's first child has been affected by cancer. Around 40% of the affected children had one sibling. In most cases caring for the siblings was handed over to either one of the parents or the grandparents. Nearly half of the study participants' children were between one and two months from the date of the cancer diagnosis. More than half of these children were boys (56%), and around 50% were under five. When the diagnosis of these children was considered, around 64% of children were suffering from hematological cancers (Leukemia – 60% and Lymphoma – 4%). In comparison, the rest of the children had been diagnosed with solid malignancies such as brain & spinal cord tumors (6%), Neuroblastoma (5%), Osteosarcoma (5%), and others (20%). When considering the services, they had received after the diagnosis, it was found that 19% of PCGs had received counseling services for at least one session and 37% had received financial support varying from a small amount to a large sum of money.



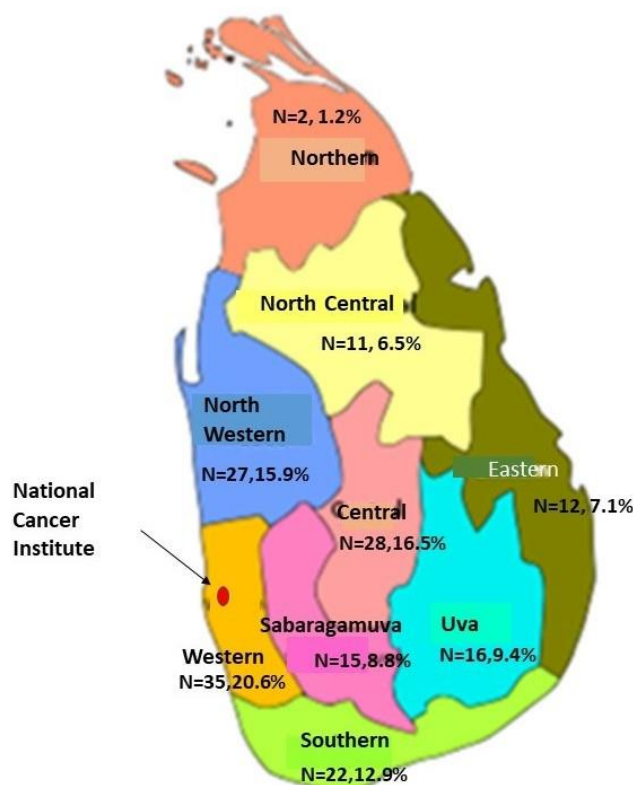


Figure 1. Distribution of Study Participants among Nine Provinces in Sri Lanka.

3.2 Psychological distress of the PCGs

When the conventional cut-off (six or more) of the GHQ-30 was considered, almost all the study participants (98%) were found to be psychologically distressed. Therefore, based on the mean score of seventeen as the cut-off, this distressed group was further classified to demarcate the highly psychologically distressed PCGs. This revealed that 61% of the PCGs were highly distressed, while 37% were mild to moderately distressed. All potentially associating factors with psychological distress were entered into the multiple logistic regression model to find any masked association by confounding. Consequently, the relationship to the ill child showed a statistically significant association ($p < 0.05$). According to this, mothers of ill children were 2.5 times more likely to report distress than caregiving fathers or grandparents (OR = 2.47, 95% CI = 1.06 – 5.820).

3.3 Knowledge of childhood cancer caregiving

Among the study participants, 18% of PCGs had good knowledge of childhood cancer caregiving. The frequency distribution of answers given by PCGs for each knowledge domain is shown in Table 1. When the knowledge domains were considered, awareness of available support services for cancer patients and families was very poor among most PCGs. For example, only 12% and 26% were aware of the availability of a social service officer and a counseling unit at the hospital, respectively. Generally, the knowledge of other aspects of caregiving was reasonably good.

PCGs who had higher educational levels ($X^2 = 11.69$, $p < 0.001$), were employed ($X^2 = 7.754$, $p < 0.01$), had lower distress levels ($X^2 = 4.88$, $p < 0.05$), and had higher monthly income ($X^2 = 3.79$, $p = 0.05$) showed a significantly higher knowledge on caregiving in bivariate analysis. All the above factors were entered into the binary logistic regression model. Multivariate analysis revealed the association between a good knowledge level of caregiving and a lower distress level (OR=2.46, CI= 1.04-5.83). Further, PCGs with higher education (OR=4.14, CI=1.73-9.93) and who were employed (OR=2.52, CI= 1.07-5.93) had good caregiving knowledge.

Table 1 Frequency Distribution of Answers given by PCGs for Each Knowledge Domain

Statement	Correct n(%)	Incorrect answer n(%)	Don't know n(%)
1. A cancer is defined as uncontrolled division of a cluster of abnormal cells	73(42.9)	25 (14.7)	72(42.4)
2. A cancer can spread to other organs of the body	140(82.4)	6(3.5)	24(14.1)
3. A Cancer is not Contagious	149(87.6)	3(1.8)	18(10.60)
4. All childhood cancers are curable	106 (62.4)	7(4.1)	57 (33.5)
5. Some childhood cancers are curable	144(84.7)	11(6.5)	15(8.8)
6. Early detection increase the rate of curing	142 (83.5)	9(5.3)	19(11.2)
7. Curing is difficult at late stages of cancers	144 (84.7)	3(1.8)	23(13.5)
8. Multimodal treatments are available for cancers	96(56.5)	7(4.1)	67(39.4)
9. Relapses are possible in some childhood cancers	139(81.8)	-	31(18.2)
10. High rate of infection during treatment	157 (92.4)	2(1.2)	11(6.5)
11. The importance of checking blood count during the treatment...	140(82.4)	2(1.2)	28(16.5)
12. Treatments reduces white cell count	57(33.5)	40(23.5)	57(42.9)
13. The importance of washing hands as a caregiver	169(99.4)	-	1(0.6)
14. The importance of good oral hygiene	168(98.8)	1(0.6)	1(0.6)
15. The importance of avoiding the crowded place for child	159(93.5)	9(5.3)	2(1.2)
16. The importance of providing hygienically prepared meals for the child	143(84.1)	21(12.4)	6 (3.5)
Factors associated with prognosis of the cancer			
17. Type of the cancer	134(78.8)	7 (4.1)	29 (17.1)
18. Stage of the cancer	123(72.4)	9(5.3)	38(22.4)
19. Age of the child	38(22.4)	35(20.6)	97(57.1)
Child's meals & nutrition			
20. giving raw fruit & vegetables	135 (79.4)	23(7.5)	12(7.1)
21. washing before eating	156(91.8)	10 (5.9)	4(2.4)
22. safety of meals from outside boutiques	138(81.2)	3(2.8)	29(17.0)
23.Importance of balanced diet	158(92.9)	4(2.4)	8(7.7)
24. hospital nutrition unit	49(28.8)	1(0.6)	120(70.6)
25. Side effects of the drugs	164(96.5)	1(0.6)	5(2.9)
Signs of infections & precautions			
26. giving Paracetamol & adequate	145(85.3)	14(8.2)	11(6.5)
27. home remedies adequate	159(93.5)	5(2.9)	6(3.6)
28. should get medical advise	160(94.1)	49(2.4)	6(3.5)
At home			
29.treatment duration of the child	155(91.1)	-	15(8.9)
30. possibility of developing life threatening complications during child's treatment	129(75.9)	15(8.8)	26(15.3)
Awareness of available supportive care services at the hospital			
31. Social service officer	21(12.4)	3(1.8)	146(85.9)
32. Counseling unit	45(26.5)	-	125(73.5)



3.4 Psychosocial needs

Among the assessed need items, under seven major need areas, the top five unmet needs identified were consecutively emotional (83%), financial (73%), informational (69%), practical (61%), and family and social support (44%). All study participants had at least one item of unmet psychosocial needs. Furthermore, these needs had varying levels of significance to them, and the fulfillment of the needs also varied vastly. Table 2 showcases the top 20 Items of significant and unmet needs ranked by proportions.

Table 2 Significant Needs and Unmet Needs: Top 20 Items (Ranked by Proportions with Significant Unmet Needs)

Rank	Item	Those rating item as important or very important (n=170)		Those with significant unmet need in item	
		n	%	n	%*
01	Need for emotional support In dealing with emotional well-being of your family members	168	98.2	141	82.9
02	Financial needs Continuing employment	152	88.9	124	72.9
03	Need for emotional support In Dealing with fears, sadness and anger	170	100	122	71.8
04	Information need Information about financial support services and how to apply for those	120	70.1	117	68.8
05	Self-caring needs Getting adequate rest/ proper sleep	108	63.1	104	61.2
06	Need of caring of other children Spending more time together with them	101	59.0	97	57.1
07	Information need Information about treatment plan	163	95.3	84	49.4
08	Information need Information about tests and investigations child has to undergo	148	86.5	76	44.7
09	Family & social support Support from other family members	105	61.4	75	44.1
10	Child caring needs Need of giving child's meals as he preferred	92	53.8	73	42.9
11	Paying non medical costs related to child's treatment Travelling	85	49.7	70	41.2
12	Meeting basic living expenses Information need	75	43.9	67	39.4
13	Information need Information about medication, benefits and side effects	156	91.3	66	38.8
14	Child caring needs Need of reducing child mental stress	74	43.2	66	38.8
15	Need for emotional support Need someone to talk to	75	43.9	63	37.1
16	Information need Information about maintaining the hygiene during chemo therapy	125	73.1	61	35.9
	Need of caring of other				



	children				
17	Attending or caring for other children in family	89	52.0	60	35.3
	Information need				
18	Information about symptoms that require hospital admission	125	73.1	60	35.3
19	Information about correct diet for the child	119	69.6	59	34.7
20	Information about the prognosis of cancer or likely outcome	163	95.3	58	34.1

Among the emotional needs considered, the need for emotional support in dealing with the emotional well-being of family members became the unmet need with the highest rating (83%), followed by the need for support for dealing with fears, sadness, and anger (72%) of the caregiver. The financial needs of PCGs were assessed under several categories. Among the PCGs, 89% rated the need to earn money by continuing their jobs as a significant unmet need. Among them, 73% of PCGs rated it as an unmet need. Furthermore, PCGs have significant financial unmet needs in terms of the expenses for treatment-related needs, primarily for specific investigations (24%), and paying non-medical costs, mainly for traveling (41%). A large proportion of PCGs (n=120, 70%) had rated the need for information on available financial support services. That need was significantly unmet among almost all needy PCGs (n=117, 98%). This was the third-ranking unmet need in the list (69% of all PCGs). In addition to that, more than 90% of PCGs had rated that the need for information on current condition and future of their child's disease (100%), treatment plan (n=163, 95%), medication benefits and side effects (n=156, 91%) prognosis and likely outcome (n=163, 95%) as significant needs while 29% (n=49), 50% (n=84), 39% (n=66) and 34% (n=58) had mentioned those as unmet respectively.

Needs related to caring for the sick child, caring for the sick child's siblings, and PCG's self-caring needs were assessed under practical needs. When the PCGs' self-caring needs were considered, a large proportion of PCGs (n=108, 63%) had rated the need to get adequate rest or proper sleep as a significant need, and almost all those needs were found to be unmet (n=104, 61%). A large proportion of PCGs (n=105, 61%) had rated the need for support from other family members and relatives as a significant need. However, 44% (n=75) of PCGs had marked that need as unmet. Almost all the PCGs had identified all six needs related to the health care provision as significant (n >165, >96%), and in most cases, those needs had been met. However, the need for health professionals who listen to (n=41, 24%), who has time to discuss (n=45, 26.5%), who are friendly/compassionate (n=36, 21%), who understand your feelings and emotional needs (n=48, 28%) were found as significant unmet needs among over one-fifth of PCGs.

All PCGs had stated the need to engage in special religious activities such as prayers and "Bodhi Pooja," wishing the child's fast recovery as a significant need. However, only 33% (n=56) had mentioned that need as unmet. Engaging in other traditional activities such as "conducting Thovilaya (a traditional exorcism ritual)" and "wearing Sura (talismans), sacred threads" were found to be a significant need among 19% (n=33). However, it was found unmet in 10% of PCGs (n=17).

Higher levels of unmet psychosocial needs were found to be associated with poor educational level ($X^2 = 12.6, p < 0.001$) and non-proficiency in Sinhala, the mother tongue of Sri Lankans ($X^2 = 5.9, p < 0.005$) in the bivariate analysis. However, during multivariate analysis, lower education levels showed a significant association with higher unmet need levels ($p = 0.001$; OR = 4.990; CI = 1.96-12.72), indicating that four times more unmet needs in PCGs with low educational levels compared to a PCG with higher educational level. Most of the psychosocial unmet need scores were found to be correlated with other unmet need scores. Among those needs, emotional and informational unmet need scores were found to correlate with each other and almost all of the other unmet need categories.

4. Discussion

Childhood cancer is increasing worldwide as an emerging health problem. At the same time, the survival rates of childhood cancers are also increasing with the invention of new treatment techniques (American Cancer Society, 2015). Childhood cancer diagnosis drastically changes the whole life of the child with the disease, the child's parents, and the whole family. Caring for the caregivers of cancer patients is an emerging facet of the cancer care



trajectory in most developed countries. To the best of the researchers' knowledge, this is the first study conducted in Sri Lanka setting targeting the childhood cancer caregiver's distress and psychosocial needs. The objective of the present study was to describe the childhood cancer caregivers' profile, including their needs, knowledge of caregiving, and psychological distress levels.

The study population for the current study was decided considering several factors attributing to the study's validity. A PCG was defined based on the available literature, and inclusion criteria were decided to minimize the sampling error. Only the PCGs between post-diagnosis one month to four-month duration were included in the study. Based on the available literature, this time window was chosen as the optimal period, reflecting the acute crisis period following diagnosis and in which new treatment modalities are introduced (Dolgin *et al.*, 2007). PCGs within post-diagnosis one-month duration were excluded to rule out the PCGs with possible acute stress disorders (Bryant *et al.*, 2011). PCGs up to post-diagnosis four-months duration were included to achieve a more homogenous sample concerning distress levels and needs attributing a minimum sample error. According to the literature, this early period is the period with maximum distress among the PCGs caring for CAAWC (Virjmoet- Wiersma *et al.*, 2008).

Though the sample of study participants was homogenous with time since diagnosis, it was a heterogeneous group in relation to the type of cancer diagnosis. In the present study, almost all participants (98%) were psychologically distressed. First, it should be stated that this value is significantly higher than the findings of similar studies available worldwide and the general population norms (Sklenarova *et al.*, 2015). As evident in the literature, finding one's own child with cancer is a highly stressful event in parents' life (Barrera *et al.*, 2012; Hoekstra-Weebers *et al.*, 2001; Sloper, 2000). This finding is not unusual in a country like Sri Lanka, where the mothers are firmly bound traditionally and culturally to care for their children, perceiving them as the center of the family.

This finding of the present study should be taken seriously as most PCGs were found to be distressed compared to evidence found in other similar studies. For example, in a similar cross-sectional study conducted in Galle, Sri Lanka, which was carried out to assess the distress level among the caregivers of children with cerebral palsy, found only 56% of PCGs as distressed (Wijesinghe *et al.*, 2014). This study is similar to the present study in several ways; both have used GHQ 30 to assess the distress among caregivers, and conventional cut-off has been used to classify as "distressed"; both studies assess the distress of caregivers of children with chronic diseases. However, the inclusion of caregivers of all Cerebral Palsy cases, not considering the time since diagnosis, might have attributed to the diluted value of the "distressed" proportion in the previous study.

Several similar studies in other countries have highlighted the higher distress levels among childhood cancer caregivers during the initial stages, which get attenuated over 6-12 months (Dolgin *et al.*, 2007; Sawyer *et al.*, 2000; Wijnberg-Williams *et al.*, 2006). For example, one study has revealed that 51% of mothers and 40% of fathers have a high level of distress at six months and one-year post-diagnosis with little change over time (Sloper, 2000). However, compared to the above study, the present study's sample was within one month to four months post-diagnosis. Hence the significantly higher proportion of PCGs with distress in the present study could be explained primarily as a result of the assessment during the early stage of post-diagnosis.

In addition to this cut-off method in detecting distress levels, higher GHQ scores indicate the severity of psychological distress (Mcdowell, 2006). Therefore, this distressed group was further classified, based on the mean score as the cut-off, to demarcate the highly psychologically distressed PCGs, in view of facilitating further analysis. This revealed that 61% of the PCGs were highly distressed, while 37% were mild to moderately distressed.

Previous studies have shown certain factors related to caregivers (age, educational level, employment status, income, family status, financial hardships) and some factors related to the ill child (child's age, type of diagnosis or treatment, time since diagnosis) and parental perception on prognosis are significantly correlating with the psychological distress of childhood cancer caregivers (Barrera *et al.*, 2012; Othman *et al.*, 2011; Rosenberg *et al.*, 2014; Sloper, 2000). However, in the present study, irrespective of all these factors, all PCGs found to be equally distressed. In other words, no factor was found to be significantly associated with the psychological distress of PCGs in bivariate analysis using the chi-square test for proportions. Furthermore, PCGs with a good education, employment, and a good income were no less distressed. Similarly, the distress levels did not exhibit any association with the cancer type or time since diagnosis. However, in line with the present study's findings, the study conducted



by Rosenberg *et al.* (2014) has not established a significant association between the distress level of parents and any parental-child demographic or disease-related factors.

However, all potential associating factors with psychological distress were entered into the multiple logistic regression model to find any masked association by confounding. Consequently, the PCG's relationship to the ill child showed a statistically significant association with distress. Mothers of ill children were 2.5 times more likely to report distress than the caregiving fathers or grandparents ($p < 0.05$). This finding is consistent with the longitudinal study conducted by Barrera *et al.* (2012) to examine the psychological distress among Canadian mothers and fathers of children diagnosed with cancer, revealing that mothers reported significantly more depressive symptoms than fathers ($F_{1,81} = 8.1, p < 0.006$).

Not assessing the caregivers' traits and related factors such as coping, resilience, illness appraisal, and optimism is a limitation when compared with the studies done earlier, which have revealed the association between those factors and levels of distress in caregivers (Dolgin *et al.*, 2007; Han, 2003; Sloper, 2000).

Among the study participants, 18% of PCGs had good knowledge of childhood cancer caregiving. Multivariate analysis revealed that higher education (OR=4.14, CI=1.73-9.93), lower distress level (OR=2.46, CI= 1.04-5.83), and having an employment (OR=2.52, CI= 1.07-5.93) as factors associating with good knowledge levels. This finding was consistent with the study conducted by Othman *et al.* in Malaysia, which showed that higher education and income levels were associated with good knowledge (Othman *et al.*, 2011). In addition, they have found that a higher level of knowledge is associated with less stress and anxiety, in keeping with the present study's findings. Within the present study sample, 38% had a higher education background (passed General Certificate of Education Advanced Level or higher studies), around 37% were employed, and 39% were less distressed.

Accordingly, the PCGs who had a good education and consequently were employed had better knowledge of childhood cancer caregiving and were less distressed. Higher knowledge among the PCGs with better education is expected. They likely have better access to new information sources. Similarly, lower distress level was associated with good knowledge of childhood cancer caregiving. Therefore, if the PCG has good knowledge of childhood cancer and caregiving, her/his distress levels will be lowered. This finding indicates that more educational interventions should be carried out among PCGs with lower educational background.

According to the present study's findings, emotional support in dealing with the emotional well-being of family members become the unmet need with the highest rating (83%), followed by the need to deal with fears, sadness, and anger (72%).

Traditional Sri Lankan's mothers are used to giving priority to the family, which might be the reason for the prominence of family members' emotional needs rather than one's own emotional needs. However, in contrast to this, a review conducted by Kerr *et al.*, including 49 studies on supportive care needs of the pediatric oncology population, reported the informational need as the first-ranking need category giving second place to the emotional needs in some other settings (Kerr *et al.*, 2004).

During the needs assessment, the need to earn money by continuing their jobs was rated as the second significant unmet need. Among the 89% of PCGs who have rated this need as significant, 73% of PCGs have rated that as unmet. Lengthy treatments with long hospitalization periods have created the issue of earnings among childhood cancer caregivers. This finding is consistent with the findings of similar studies (Elcigil & Conk, 2010). This issue is exaggerated when the PCG or spouse suffers a job loss or not working during the treatment period (Adler & Page, 2008).

Study limitations: Regarding the study sample used in the cross-sectional study, the study sample was homogenous regarding the time since diagnosis. Still, it was not so with regard to the type of cancer diagnosis. This might introduce significant variability in the sample. However, this kind of diversity is generally accepted in childhood cancer research, considering the limited availability of subjects.

Though the sample size used for the cross-sectional study was large compared to the other similar studies, the absolute number of subjects was not so large. This might be a reason for failing to confirm the already established associations between distress levels and caregiver and care recipient factors. For example, we failed to confirm the



association between the caregiver's age, education, income, child's diagnosis, time since diagnosis, and distress levels.

Data collection was done through an interviewer-administered questionnaire. Though the interviewers were trained on data collection, interviewer biases cannot be completely excluded. Likewise, since the interviewers were pre-intern Medical Officers who were not attached to the NCI Maharagama, as they belonged to the category of 'health professionals,' respondents might not have provided accurate information for specific questions such as the questions related to the quality of service provided by health care professionals at NCI.

For this study, participants were recruited from only one institution, which might affect the study's external validity. In addition, this would limit the generalizability of the study findings to the other childhood cancer caregivers who are not attending NCI, Maharagama, in Sri Lanka.

During this study, a generic outcome measure was used to assess the distress level; this might have influenced the prevalence levels of psychological distress among the study participants. During the cross-sectional study, the personal factors of caregivers, such as personal traits, coping ability, and psychological resources, such as resilience, optimism, and self-efficacy, were not assessed. This might have impacted the correlations of distress levels and needs. Assessment of knowledge on childhood cancer caregiving was done on selected domains, and each domain was given an equal score, even though their impact was different.

5. Conclusion

The following conclusions were drawn from the present study;

- 1) The top five unmet needs among primary caregivers of children with cancers consecutively were emotional needs, financial needs, informational needs, practical needs, and need for family and social support. All study participants had at least one item of unmet psychosocial needs.
- 2) The prevalence of psychological distress among PCGs of CAAWC attending NCI, Maharagama, in the early post-diagnosis period was high (97.6%)
- 3) The prevalence of good knowledge of childhood cancer caregiving among PCGs of CAAWC was low and awareness of the available supportive care services was very poor among most PCGs. However, the good knowledge level on caregiving was associated with lower distress levels of the PCGs.

Implications for service provision:

- 1) As almost all childhood cancer caregivers were distressed and had multiple unmet psychosocial needs during the early post-diagnosis stage, steps should be taken to initiate screening for distress and the needs of all PCGs of CAAWC as early as possible to address them.
- 2) As the knowledge of caregiving was found to be low, steps should be taken to address the knowledge gap through suitable interventions.

As caring for caregivers is not a prioritized area in the present health system, effort should be taken to incorporate "caring for caregivers" as an integral part of cancer care in Sri Lanka. For this to be implemented, National guidelines should be developed, incorporating psychosocial support for the patient and family as an integral part of the routine cancer care plan.

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