

Psychosocial needs of childhood cancer caregivers attending the main cancer treatment center in Sri Lanka: A qualitative assessment

Sachintha Dilhani W.N.* , Sivayogan S.** , Jayamal De Silva** , Suraj Perera**

* National Cancer Control Program, Ministry of Health, Sri Lanka

**Emeritus Professor, Department of Community Medicine, Faculty of Medical Sciences, University of Sri Jayawardenapura

**Department of Psychiatry, Faculty of Medical Sciences, University of Sri Jayawardenapura

**National Cancer Control Program, Ministry of Health, Sri Lanka

DOI: 10.29322/IJSRP.12.01.2022.p12140

<http://dx.doi.org/10.29322/IJSRP.12.01.2022.p12140>

Abstract- Diagnosis of childhood cancer significantly changes the lives of those children and their family members. A family caregiver plays a significant role in providing most of the care to their ill patient, in addition to the care provided by the health staff. Identifying and addressing these psychosocial needs of primary caregivers (PCG) of children and adolescents with cancers (CAAWC) is emerging globally as a component that should be incorporated into quality cancer care.

This study aimed to describe the psychosocial needs of primary caregivers of childhood cancer patients at the National Cancer Institute, Maharagama (Apeksha Hospital at present), in Sri Lanka.

Method- A qualitative study through Focus Group Discussions (FGD) was conducted among primary caregivers of children and adolescents with cancer at the main Cancer treatment center in Sri Lanka. Data were transcribed verbatim, translated to English, and analyzed using thematic analysis.

Results - Twenty-two PCGs participated for FGDs, and saturation point was reached by the fourth discussion. PCGs of CAAWC described their psychosocial needs at the time of the discussion and the emerged themes which could be identified during the analysis echoed the psychosocial needs already known in the literature as follows; Financial needs, Emotional needs, Informational needs, Social needs, and Practical needs. In addition, caring for the siblings emerged as a new category which is usually grouped under practical needs.

Conclusion - Almost all PCGs of CAAWC in Sri Lanka, who were at the early stages of diagnosis had multiple unmet psychosocial needs, which required the early attention of health care professionals.

Index Terms- Childhood cancer, caregivers, psychosocial needs, Sri Lanka

I. INTRODUCTION

The incidence of childhood cancer is showing an increasing trend globally and locally. Diagnosis of cancer in early life affects the patient and the whole family in an undesirable way (1). Every childhood cancer patient requires at least some care from an informal caregiver.

The Informal caregiver is defined as a family member or friend who is not paid and provides physical, emotional, financial, or other support to the care recipient. Among those caregivers, the most responsible for the patient's day-to-day care and decision-making is known as the primary caregiver (2).

In addition to the care provided by the health staff, a family caregiver, mostly a parent or a relative, plays a significant role in providing most of the care to their ill patient (70% -80%) (3).

They involve themselves in many facets of patient care, from cancer diagnosis throughout the active treatment period to follow-up. These caregiving activities include but are not limited to mobility, organization of appointments, medication acquisition and dispensing, symptom management, meals and nutritional assistance, assisting with personal care, managing finances, supervision of treatments, transportation, emotional support, coordinating care, and communication with providers (4)(5)(6).

Though the "psychosocial needs" term literally could be interpreted as referring to all psychological (mental health, emotional issues) needs, as well as all social needs (Financial needs, family/ social relationship, etc.), the psychosocial needs of a cancer caregiver could be categorized in several ways. The needs have several dimensions which include informational needs, financial needs, emotional needs, personal needs, spiritual needs, social needs, practical needs, child care needs, and health professional needs (7) (8).

These psychosocial needs of caregivers have been identified as highly correlating with the outcome of caregiving for the caregiver and care recipient (9) (10).

Therefore, there is a need to identify the psychosocial needs of family caregivers, which should be addressed to improve their health and provide the best possible care for the care recipient, leading to patient and caregiver satisfaction (11).

Although many studies on caregivers are available worldwide, research on caregivers is limited in the Sri Lankan setting, and there is a dearth of information highlighting the caregivers' burden of caregiving to childhood cancer patients in Sri Lanka.

Therefore, this study aimed to explore the psychosocial needs of primary caregivers of children and adolescents with cancers in Sri Lanka.

This study was the first component of a two-phase research project, which was followed by a cross-sectional study in phase one and an interventional study in phase two, and carried out from year 2017 to 2018.

II. METHODS

A qualitative descriptive design was used to explore the psychosocial needs of PCGs of CAAWC. Data were collected through FGDs.

The National Cancer Institute (NCI) Maharagama, was selected as the best setting to conduct this study. NCI is located about 16 km away from Colombo, the commercial capital of Sri Lanka, and it is the largest cancer hospital in the country at present, with specialized treatment modalities for any type of cancer. Further, the NCI Maharagama is the main center with specialized pediatric oncology treatment facilities in Sri Lanka. The pediatric unit of this hospital consists of four major units (wards).

Purposive sampling was carried out and PCGs from all four pediatric units' inward patients who were eligible and willing to participate were recruited. PCGs of CAAWC who had a confirmed diagnosis of cancer at least one-month post-diagnosis up to four-months of diagnosis and under active treatment were invited for the discussions.

A focus group guide including semi-structured questions, was developed based on the literature and used to explore the psychosocial needs of PCGs during the discussions.

A quiet and comfortable place in a corner of each pediatric ward was selected for conducting FGDs. Each interview took about 1 to 1 ½ hour.

At first, the moderator (the Principal Investigator of this study) welcomed all the participants and, following a brief introduction of the study, explained the ground rules of the discussions, creating a permissive and open environment to express the participant's views.

The session began with the opening question of the topic guide, which was a broader and easy question; "What are the psychosocial needs you have/had as a primary caregiver of a child/adolescent with cancer after diagnosing cancer in your child?"

All the participants were encouraged to talk, but the discussion focused on the key issues.

The rest of the questions were designed to probe and explore the needs identified as psychosocial needs of cancer caregivers in the literature. In addition, a few questions were included to clarify the types of information and support they need to face this situation better.

Interviews were audio-recorded, and notes were taken during the interviews. The key points identified during the session were summarized and presented to the participants for further clarifications at the end of the session.

No incentive or compensation, financial or otherwise was offered.

PCGs who were highly depressed were referred to the consultant psychiatrist with their consent for further assessment and management of the condition.

All FGDs were conducted during the evenings to ensure that the unit work and the child's routine care were not disturbed.

Data analysis

All audio recorded data was transcribed verbatim at the end of each interview by the principal investigator (PI), and thematic analysis was carried out. The transcribed data was read thoroughly, and areas with meaning were marked, and these areas were condensed into meaning units, and codes were assigned.

Data were coded by PI, and those codes were combined into categories. Finally, these categories were grouped under themes.

Data analysis was carried out manually without using any analysis software programs.

Research Ethics:

Ethical clearance was obtained from the Ethics Review Committee of Post Graduate Institute of Medicine Colombo, and administrative clearance was obtained from the head of the institution of NCI. In addition, informed written consents were taken from all the study participants, and confidentiality of the data was maintained throughout the process.

III. RESULTS

An average of five to eight participants participated in each discussion. The saturation point was reached by the fourth FGD, which was conducted covering all four pediatric oncology units.

Characteristics of FGD participants

Twenty-two PCGs participated in the FGDs, representing eight out of nine provinces in the country and among them, 14 were mothers of sick children while others were four fathers and four grandmothers. Almost all mothers and grandmothers were housewives. The majority of the children had Leukemia and were below the age of 10 years.

Socio-demographic characteristics of the PCGs are given in Table 1.

Table 1 : Basic Characteristics of FGD Participants

Participant characteristics (n= 22)	
Age range :	26 to 61 years
sex	18 – females, 04 –males
Relationship to the child with cancer	
Mother	N= 14
Father	N=4
Grandmother	N=4
Occupation of the PCG	
Housewives	N=18
Drivers	N=2
Farmer	N=1
Retired Army officer	N=1
Child's characteristics	
Age of the child	
0-5 years	N= 5
06-10 years	N= 8

11-15years	N=4
16-19 years	N=4
Type of cancer	
Cancer type	
Leukemia	N=15
Lymphoma	N= 2
Solid tumors	N=5
Province	
North Western	N=4(Wennappuwa, Chillaw, Kurunegala, Alawwa)
Central	N=3 (Kothmale, Gampola, Dambulla)
Southern	N=6 (Mathara, Weeraketiya,Galle, Hambanthota)
Uva	N=3(Badulla, Sevanagala,Mahiyanganaya)
North Central	N=2 (Wilpaththu, Polonnaruwa)
Western	N=1 (Colombo)
Sabaragamuwa	N=2 (Kegalle, Godakawela)
Eastern	N=1 (Akkareipaththuwa)

Psychosocial needs of PCGs of CAAWC as identified through the qualitative assessment

PCGs of CAAWC described their burning psychosocial needs at the time of the discussion and themes which could be identified during the analysis, echoed the psychosocial needs already known in the literature as following; Financial needs, Emotional needs, Informational needs, Social needs, and Practical needs. In addition, caring for the siblings emerged as a new category grouped under practical needs.

Those identified themes, categories, and subcategories are displayed in Table 2

Table 2: The List of Themes, Major Categories, and Sub Categories, Emerged Through FGDs with PCGs of CAAWC

Theme	Major categories	Subcategories
Financial	Income	Difficulties to attend to work / No income Limitless leaves Problems with retaining the job
	Expenses	Expenses for treatments <ul style="list-style-type: none"> - Drugs - Investigations - Surgeries Expenses for treatment-related other things <ul style="list-style-type: none"> - Transportation - Accommodation - Meals Household expenses

Practical needs	Child caring	Handling Child's stress Communicating with child Support in child caring Continuing child's education Providing child's meals as he/she preferred Need of hot water for cleaning little ones
	Caring for siblings	Looking after other children at home Lack of time to spend with them
	Self-care	Poor sleep/rest/continue treatment for their illnesses.
Emotional needs	Self	Fear Sadness Anxiety
	Family members	Distress among spouse and siblings
Family & social support	Spouse	Understanding the situation Dedication to care/relationship
	Family& relatives	Support in facing the situation
Informational	Disease-related	Cause for the cancer Prognosis Treatment plan
	Available resources/ supportive care	Financial Counseling Other supportive care Facilities available at the hospital
Spiritual	Religion-related	Advice of religious leaders Prayers "Bodhi pooja" Local rituals Belief
Healthcare needs	Staff	Listening Kind Loving & caring Providing needy information
	Infrastructure	More free accommodation facilities More spacious wards Elevator facility for upstairs ward Child cancer treatment centers for far away provinces

Financial Needs

Most of the caregivers defined their financial status as "poor," and the majority of PCGs described financial needs as the top-ranking need among them.

They mentioned that their financial status is worsening after the diagnosis of the child's cancer due to the following reasons:

1. Income

In some instances, the father, the family's sole breadwinner, had to become the PCG of their sick child. It is primarily due to the inability of the mother to be with the sick child as the mother had to take care of younger siblings. This has led to a significant financial crisis with no income. Similarly, although the mother was staying with the child, the father could not still earn as usual since the father had to do frequent hospital visits and take care of the other children who were at home in the absence of the mother. These tasks demanded time off from work.

Therefore, family income has been affected adversely in most of these families. An excerpt from a discussion illustrates the point clearly as depicted below.

"Now my major need is earning; I am a farmer, in addition to that, I used to do some casual work for a living. Now I have to stay with my child, the child's mother has to look after the younger one who is too little to look after by somebody else. Therefore, currently, we do not have any income, it is a huge problem, and my family is facing a lot of financial issues." - A father.

2. Expenses

a. Expenses for treatments

On top of the deprived income, increased expenses following the diagnosis had aggravated the financial needs of these families. Though the health services are provided free of charge at the point of delivery in Sri Lanka, many other expenses have led to this financial crisis.

Most PCGs praised the free health system providing medicines, investigations, and most facilities free of charge, while few PCGs said they had to pay for specific investigations and medicines available only in the private sector.

Since the facilities for several treatment modalities, such as certain transplant surgeries, are unavailable in Sri Lanka, those surgeries are planned to be performed in other countries. However, the costs for these surgeries are unbearable for an average person, and it was stressed by PCGs who were waiting for this kind of surgery for their ill child. This adds to emotional distress; when a treatment is available somewhere else in the world, but could not be accessed.

"Planned to do a bone grafting for my daughter's leg bone cancer in India, we need 30 Lakhs for that. It is a large sum of money" - A father.

Some of the care givers have received donations from the hospital staff or other well-wishers during the hospital stay to fulfill their requirements to some extent.

Their views on expenses for the child's treatment reflect the merit of having a free health system in Sri Lanka.

b. Expenses for Treatment-related needs

Though the PCGs do not have to pay for the treatment, they face financial problems when fulfilling the treatment-related other needs. For example, most of the children had to stay in the hospital for a long period of time or make frequent visits to the hospital. For PCGs and children who live at a distant place from Colombo, expenditure on travelling back and forth was a significant burden. Most of them used the public transport system to travel to the hospital though it is not comfortable to the ill child. They could not think about other options such as hiring a vehicle because of the unbearable costs. They had to tolerate all the difficulties their child endured whilst using often overcrowded public transport just to come to the hospital.

"It is so expensive to hire a vehicle from Alawwa (approximately 80km away from the hospital), if so we have to pay around Rs: 6000 for the taxi for the journey. Therefore, we used to travel by train, and I used to hire a taxi only from the railway station to the hospital" - A mother from a rural area of Kurunegala District

In some instances, though the child is discharged from the hospital, he/ she should come to the hospital once in two days for treatments. PCGs pointed out the need for accommodation for those living far away from the hospital in this kind of situation.

They are provided with accommodation facilities free of charge within the hospital premises through Courage, Compassion, and Commitment (CCC) foundation, known as CCC house. However, according to the PCG's views, they face a big problem when this facility becomes full to the capacity. Then they have to find another outside/ private, usually a paid place for accommodation, sometimes for higher prices, or plan to go back home.

"Sometimes we do not get a room in CCC house also, for instance, now yesterday also, the child next to mine who was from Anuradhapura (approximately 210 km away from hospital) was discharged, CCC house was houseful, and he could not get a room there, so his mother decided to go home, she had to hire a vehicle & it had cost around Rs:10,000" - A mother

Emotional needs

Fear, sadness, and uncertainty were the most frequently cited emotions by PCGs during the initial post-diagnosis period. Some PCGs had described it as a totally depressed period, while some had mentioned it as the mental status of "zero" level.

Time had become the healer of their emotional conflict. Some PCGs pointed out that fear or sorrow goes away with time by seeing the child's clinical improvement. In addition, seeing other children with the same condition during the hospital stay and talking with their caregivers had contributed to easing and dealing with their emotions.

Only one participant pointed out the relief she experienced with the counseling, while others have failed or not received the chance of getting the benefits of counseling sessions.

"Initially, they sent me to counseling unit for counseling, and doctors there discussed my issues with me. But I could not attend that on the next date given, because the child was on treatment, with needles in the hands; the child had much body aches too so that I could not attend those sessions after that" - A mother

In addition to the PCGs' emotional status, the emotional needs of ill children, spouses, and siblings were also highlighted in the discussions.

Though only one of the parents is staying with the ill child, their spouse also suffers emotionally from this unexpected diagnosis as a result of overwhelming responsibilities which come over to their shoulders. Sometimes worrying on the spouse's part has led to emotional and physical deterioration of the health condition necessitating even treatment.

The emotional well-being of the ill child is affected due to various factors. Among those, interruption to their usual schooling and other day-to-day routines were found to play a significant role. Furthermore, mothers who participated in discussions revealed an aspect that we never thought of or considered harmful to others in any way: visiting a child during their hospital stay by their parents/relatives frequently.

According to some PCGs, most of the children admitted to NCI Maharagama reside far away. Hence, their family members are unable to visit the child regularly due to distance factor and financial barriers, and they usually visit once a week or more apart. However, the families of children who live close by or financially strong visit their children daily or even twice a day.

A child who is not getting this opportunity of seeing their families frequently is prone to get depressed by seeing the other children with that opportunity. As a mother described this situation :

"Close by people visits their children several times per day, but as we are living far away, nobody can visit us daily. So, they come only once or twice per week. So, when our children see the visitors of other children, they feel sad and get depressed, what to do?"- A mother.

Caregivers' views reflected their worries towards the suffering of their healthy children at home due to the absence of the mother/father for an extended period. This is described in detail under the practical need category.

Informational need

These discussions revealed three main areas of information they deemed important; Information on the disease, resources / supportive care, and information on facilities available at the hospital.

PCGs required information on the disease; they were keen on knowing the cause of the child's cancer and also whether cancer can be cured or not. Knowing about the curability and the disease course has supported them to relieve their sadness, fear, and overall distress.

While some PCGs are satisfied with their knowledge of the child's disease, some said they are not adequately aware of the condition. Medical officers and the nursing officers of the relevant ward were their primary information providers on disease and treatments.

Few participants from the lower socio-economic background believed that they were not educated enough to ask questions from doctors regarding the child's illness. Therefore, they tend to believe what doctors say, as the final verdict without further questioning, though they had many questions in their minds.

"as I am not educated enough and not much knowledgeable to ask questions, am not asking anything from the doctor, but when my

son comes, he asks, and usually we get the answers for those"- A Grandmother.

Some PCGs have referred to books to get information on the child's disease. However, almost all PCGs agreed that it would be more helpful if a booklet was available for them to refer to pediatric cancer caregiving.

Some PCGs stated that medical officers and nursing officers provide necessary information adequately and accurately when they ask for it.

Few participants emphasized the need to orient the hospital setting for newly registered patients and their families to avoid searching for particular places and services.

When we discussed the resources / supportive care available to them, most were unaware of available financial and psychological support services.

Although they felt the need for support, they were unaware of places/ persons they should meet. Most cited the need for financial and psychological support, but they have not heard of social service officers helping to obtain donations and other financial benefits they deserved. They have not heard of the Counseling unit of the hospital or even the word counseling to reduce their psychological suffering.

"We know nothing about available supportive care services for us, and actually we do not know from where or whom to ask for those information"- a mother

When we consider participants' views, provision of the above information to the PCG's of CAAWC will be a key to reducing their distress in many ways.

Practical needs

Needs related to the sick child caring, caring for other children, and self-caring needs were categorized under this theme. In addition, if somebody met difficulties in fulfilling a task and did not belong to other major need categories, those needs were categorized under this theme. Among these subcategories, most PCGs' main concern was caring for the sick child's sibling. It has become a significant issue among hospitalized parents.

The majority of PCGs spoke about not having a proper way of caring for ill child's siblings. Though few PCGs had extended family support, few were not getting that opportunity. Few PCGs were getting support from relatives, while in many cases, the parent who was at home was the sole caretaker of other siblings, overwhelming his / her responsibilities.

Most PCGs had two to four children, including the sick child. Some did not have grandparents or relatives living nearby to spend at least a little time with these siblings. When the families had very young siblings, including newborns, it was challenging to replace the mother's role with anyone else other than the mother; therefore, in such families, most of the time, the father or grandmother stayed with the sick child at the hospital as the PCG. Therefore, the responsibility of the other siblings was not much of a problem only in the group mentioned above.

In almost all the other cases mother was staying with the sick child, and then the issue has arisen. If they had grandparents living with them, the problem would have been almost resolved. However, in the unavailability of such close relatives, the father had to look after siblings while trying to continue his job and make the ill child's hospital stay comfortable by visiting him as required. Some

PCGs had received the support of close relatives, and siblings were cared for by them, while some had no one to look after their children at home.

"I have a 12 years old daughter and four-year-old son at home. I managed to find a babysitter, an old lady to look after them and I paid her. But recently, she also left. Now my children are with one of my friends" (tearfulness) – A mother

The above facts showcase the need to make the general public aware of supporting a family with a child with chronic ill health. Most mothers were worried about the siblings' safety staying at home without the mother's care. When reviewing the mother's comments, it was clear that mothers have noted the changes in psychological status among siblings, with the diagnosis of cancer in their brother/ sister making the family apart. Lack of mother's love and care had made some children's lives miserable.

The education of the sick child's siblings also had been affected due to this situation. However, finding a solution to this problem was somewhat tricky. Almost all the mothers with children other than the sick child expressed their worries about those siblings' safety, education, and psychological impact in detail.

"My other daughter lives with her aunt now. But she is not happy with them. She lives there with some kind of fear in her mind. I feel that she has got affected mentally. So, I am worried about her emotional status rather than her studies"- A mother.

These issues had got worse when the sick child's sibling was an adolescent girl. Two parents expressed their worries about keeping a young girl reaching puberty at home alone, without her mother's love, care, and protection since it is not acceptable according to Sri Lankan culture and traditions. However, they had no options to choose other than doing that.

When going through the PCG's views on sick child caring, few needs could be identified repeatedly. For example, while some PCGs worried about the sick child's education, other groups worried about providing meals to the child, getting hot water to clean them, etc.

They described the situations they need support to handle when caring for a sick child. At first, mentioned the child's emotional needs created with the sudden change in his /her life with the diagnosis. According to them, some children were fed up with the hospital stay, and they insisted on going home since they wanted to go back to their everyday life, including schooling.

"My little one is fed up with this hospital stay now, and He cannot understand his condition. He wants to go back to school. he is eight years old now, Not attended to school for the last three months"-A mother

Some of the PCGs spoke on the issue of providing meals to sick children. Though meals are provided free of charge from the hospital, children sometimes refuse to eat those, making the reason tasteless. Then the parents are faced with the problem of providing them with something palatable. According to the parents, doctors have advised them not to give food brought from outside to sick children except when it is homemade. However, families living closer to the hospital bring meals to their children as required. Then for the people who are living in distant areas, such as Dambulla, Monaragala, Mannar are unable to do this, since it takes

at least 8 – 12 hrs to complete their journey from home to the hospital using public transport; they cannot bring homemade food to the child without it getting spoiled. Hence, though it is not suitable for the child's health to fulfill their request, PCGs are forced to buy something from eateries and pastry shops.

As a solution to this, hospital management has provided a place for mothers who want to cook themselves for their little ones. However, after getting the inputs of PCGs, it was clear that this small kitchen was underutilized by PCGs for several reasons, including unawareness about this facility.

Few PCGs described their need for the continuation of sick child's education. Some children had been preparing for major examinations such as the General Certificate of Education (GCE.) Ordinary level (O/L) or GCE Advanced level (A/L) when they were diagnosed, and though they missed the first attempt because of the diagnosis, their parents wish them to prepare for the following year's exam. Some of the parents were very optimistic, and their plans on the child's education with the recovery were well expressed during the discussion. Like all other parents, they also were dreaming about their child's future.

PCGs self-care needs are identified among caregivers in the literature; the participants of these discussions also described their self-care issues such as lack of proper sleep, no time to rest, no meals on time etc. However, these participants do not care much about their own needs. Their only hope is the child's recovery, irrespective of all the difficulties they are going through

"At the beginning, I was always crying, did not eat, did not even comb my hair, now it is already one and half months I have been in the hospital, during which period I could not get proper sleep at all"- A mother

Spiritual needs

Local rituals play an important role in treating ill people in Sri Lankan tradition. People engage in various activities depending on their religion, wishing for a rapid recovery. This fact was supported by the comments given by the PCGs of CAAWC. Primary caregivers who were Buddhists mainly engaged in Bodhi Pooja, which is a form of worship found in Buddhist culture in Sri Lanka, wishing for the rapid recovery of the child. As the PCG was at the hospital with the child, their family members, relatives, and neighbors engaged in these activities. Catholic people and Muslims also have engaged in wishing the best for the ill child through prayers and other rituals.

All these groups believe that they are getting relief by engaging in these rituals.

"We are conducting Bodhi Pooja, and these lead to a great relief for us; by now, my family has conducted more than 10 Bodhi Poojas. I believe that these will lead to my child's recovery."-a mother

Need for family and social support

Primary caregivers of CAAWC described the support they are getting from their spouse, other family members, relatives, and neighbors. Except for a few mothers, other PCGs were satisfied with the support they received from their spouses, and spouses were extremely helpful and understanding. However, few mothers described poor understanding and support from their spouse, and among them, one mother expressed her views as follows;

"Sometimes, he scolds me when I did not call him; we only know what we are doing here. Sometimes, when some intravenous drugs continue, I have to monitor the child continuously for 12 hours. The husband does not know what is going on here, and he does not even try to understand my situation here."

Though some people get good extended family support, some are not getting that. In addition to that, some relatives and neighbors of the affected families have also become so helpful, and they have supported the PCGs by caring for the sick child's siblings, engaging in rituals wishing rapid recovery to the sick child, and supporting to be financially strong. Following are the views of a mother related to support they are getting from close ones;

"I am not doing a job, my husband was working in Italy, but he came back because of the child's illness. All his relatives are in Italy, and they are helping financially, so we are having relatively fewer financial issues, and I am getting good support from my relatives, what they want is to get the child cured somehow or other." - A mother.

Health care needs

Things that people expect from a health care facility and health professionals could be categorized under this theme.

From admission to the hospital, patients and caregivers become members of the health care team. Attempted to identify their health care needs as follows;

The majority of the PCGs were satisfied with the care provided through the hospital, and they appreciated the health care services provided to them, almost everything free of charge. According to their views, all the staff, including consultants, other medical officers, and nursing officers, are accommodating, kind, caring, and understanding. It is as follows in their own words;

"Service should be appreciated."

"Do not know about the other wards; doctors and nurses all are good in this ward."

IV. DISCUSSION

Psychosocial needs of cancer caregivers and the impact of unmet needs have become a significant concern during the recent past, mostly in developed countries; this is well supported with a growing body of literature (12) (13) (8).

During this study, a qualitative assessment of psychosocial needs through conducting of four FGDs was carried out.

We found few additional categories of needs in addition to the ones found in literature. These needs comprised of financial, practical (needs related to sick child caring, caring for siblings of the sick child and self-care needs of PCG), emotional, family and social support, informational, spiritual, and healthcare-related needs, which were consistent with the evidence in the literature (12) (14) (8).

Three subcategories were found related to emotional needs during discussions of the present study; PCGs had felt a need for support to deal with their own emotions, sick child's emotions, and the emotions of family members.

PCGs have reported fear, sadness, and uncertainty as frequent emotional needs to be dealt with this unexpected diagnosis. In addition, conversations with them revealed their need to appear strong in front of the child to minimize the child's suffering, even though parents themselves wanted to grieve. Further, they revealed the practical barriers in accessing available support such as counseling during this period. At the same time, they claimed that this severe distress goes away with time, which is a well-accepted fact in the literature (15) (16) (17).

Similarly, they have reported seeing the other children with cancer and sharing their difficulties with the other caregivers as modes of relief of emotional distress. This sharing of ideas and support with other caregivers is a common finding found in the literature (18), and this is a form of peer support that will help cope with emotions of distressed PCGs with a child's diagnosis and consequences (12). Similarly, they have stated that "words of doctors" explaining the child's condition to them, including the prognosis per se, is a distress reliever. Again, this indicates the immense use of realistic reassurance and a prognosis prediction with timing to the emotionally overwhelmed PCGs.

A hidden cause for the emotional suffering of the sick child has come up during the interviews; those children who were residing far away from the hospital were not getting frequent visits from their families due to distance and financial issues. When these children see the other children who live close by, facilitating their family members' frequent hospital visits with foods and toys, they feel sad and involuntarily suffer. This is not a fact found in the literature, and this might be a finding that is specific to this setting. Unless the children were in separate rooms, this disparity would be there. It is challenging to find a simple solution to this kind of an issue. Nevertheless, the possibility of creating peer support among the PCGs would help to mitigate the situation.

Siblings of the ill child are the third party who suffers emotionally by deprivation of their chance to be with loved ones. Deprivation of mothers' love and time to spend with their loving family may lead to unhealthy emotional relationships among siblings of the ill child, which will badly affect their future. This finding followed similar studies (18).

In summary, witnessing the suffering of their beloved child, knowing the life-threatening nature of the disease adding to other family commitments such as caring for other children with the additional financial burden altogether contribute to this substantial emotional distress of the PCGs of CAAWC. Therefore, they need support in coping with emotional needs through peer support programs, counseling /psychotherapy at the individual or group level, and, if indicated, pharmacological management (12).

When the financial needs are considered, lengthy treatments with long hospitalization periods have created the issue of loss of income/ earning among childhood cancer caregivers. This finding is consistent with the findings from similar studies (18). However, this issue is exaggerated when the PCG or spouse suffers a job loss or does not work during treatment (12).

High costs for medical treatment and lack of / inadequate medical insurance are the primary sources of economic/financial burden among childhood cancer caregivers in most other countries (12). However, this is not valid for a country like Sri Lanka, in which a free health care system exists.

Moreover, travel expenses have become a significant issue among most study participants as they reside far away from the hospital. This leads to a major expense to bring the child to the hospital; if they hire a vehicle, the cost varies from thousand to ten thousand Rupees depending on where they live. Therefore, they tend to use crowded and congested public transport, ignoring the child's discomfort when coming to the clinics. During the interviews, some stated with a sigh, "If we had this type of hospital in our district too...", though they knew that it would not come true in the near future.

Provision of health care information to the patient, family member, or caregiver is considered essential in cancer care. And the informational needs of caregivers of pediatric cancer patients have been categorized as information about the illness process, prognosis, treatment plan, possible side effects of the treatments, discharge planning, home care needs and on injections, nutrition, and on many more aspects (19) (20). In parallel to the literature, present study revealed three subcategories of information needs; information on the disease itself, information on resources /supportive care, and information on facilities available at the hospital. PCGs expressed their views on disease-related information, and basically, what they wanted to know was the cause for developing cancer in their children and whether it can be cured or not, and how long it will take.

Further, these discussions revealed the ignorance of PCGs on available supportive care services.

A qualitative study has been conducted among parents of children with cancer in Sweden to describe the parents' experiences of information acquisition and use related to the child's diagnosis. The researchers have highlighted the need for paying extra attention to the parents' informational needs by clinicians. Equally, they have emphasized the importance of the continuous provision of information throughout the cancer journey, beyond the early phase of the diagnosis, modifying the content and quantity of information according to the need (21). Therefore, providing the correct information to the caregivers at the right time is vital for the patient and caregiver's betterment.

As revealed during the discussions, the low health literacy was due to the unavailability of specific books and reading material on childhood cancers at the ward setting or not knowing about a specific book to read.

As they were hospitalized with the child, for a long term, they were reading whatever was available at the wards for them to read, and during the discussions, they specifically mentioned the benefits of having some booklets written on childhood cancers so everybody can read it and can pass it on to the next comer.

Showing the perceived power difference between the PCGs and staff, few PCGs who participated in the discussions have revealed that they are not asking questions from doctors about a child's illness, as they feel that they are not educated enough to do so. This communication gap still exists in the Sri Lankan community that healthcare providers should address.

In this study, three categories of needs emerged during the discussions under the Umbrella term of practical needs. They were PCGs' self-caring needs, caring siblings of the sick child, and needs that arose during sick child caring.

PCGs worried a lot about rest of their children at home with either the other parent/grandparent or with some relative. Again, this was an area where PCGs talked in-depth, similar to financial issues during the interviews.

If the other sibling was a newborn, requiring breastfeeding, or if that one was a girl at the age of puberty, fathers/grandparent was staying with the sick child allowing the mother to stay with the sibling. Their views display the Sri Lankan cultural beliefs regarding a girl's attainment of puberty.

In addition to this, views of the PCGs revealed that their worries about siblings' deteriorating mental status, educational status, and safety, with this unexpected event, occurred in their families, making them apart. These findings related to siblings of the sick child were similar to the findings within the literature (18).

Under the practical needs, PCGs faced specific needs related to caring for a sick child. Among those concerns, needs related to meals was mainly specific to the study setting. Creating peer support groups would help mitigate this kind of issues. This form of support likely takes place informally as most parents will bring some food that could be shared among other children as well.

Among the practical needs, we found that, the self-caring need was the least discussed area compared to other practical needs which are not directly related to the caregiver. PCGs clearly stated that they do not want any facility for them, and what they only want is the child's cure. As per the literature, usually, caregivers tend to put the needs and interests of the patient above their own (13). The findings of this study repeatedly proved that fact.

When considering their views on self-care, it seems that "time out" or a break for PCG is severely lacking in our setup.

Spiritual needs have been defined in the literature as needs related to the "meaning that life holds a sense of purpose, a relationship with a Higher Being" (14).

Based on the Sri Lankan cultural background, people tend to believe an unseen power of religion bound local rituals in curing a sick person. This fact was supported by the findings of this study, in which they have described their ways of connecting to the religion in wishing a speedy recovery. Bodhi pooja and prayers were the commonly mentioned activities, which were carried out to fulfill the spiritual needs of PCGs and the whole family.

This was elaborated during the discussions, explaining that conduction of these things is voluntarily carried out by family members, relatives, neighbors, or friends.

In a disease like cancer, patients and caregivers need immense family and social support to cope with the situation.

Most PCGs mentioned the poor support they were getting even from their close relatives during that period. In some cases, it was clear that the understanding of the situation by the partner was not satisfactory. Unfortunately, few mothers expressed their views on this aspect during the discussions, and according to them, lack of overall understanding of the circumstances related to the child's condition among the couple sometimes has led to the family dispute, despite the child's condition. On the other hand, most of the PCG's appreciated the support extended by their partners. In addition to this, the support provided by health professionals was very much appreciated. Consistent with this, mothers of children diagnosed with cancer in Turkey have reported the immense support they received from their spouses and the support extended from health care professionals and other family members (18).

Furthermore, needs related to health care provision play a vital role in cancer caregiving.

Things that people expect from the health care facility and the staff were assessed during the FGDs, and fortunately, most of the

participants appreciated the health care staff and seemed satisfied with what they were getting. However, reviewing their views indicated that their only expectation from the hospital staff was the child's cure and not anything else.

V. CONCLUSIONS

In line with the literature, identified major psychosocial need categories of PCGs of CAAWC attending the main pediatric cancer treatment center in Sri Lanka are financial, emotional, informational, social, and practical needs. These needs should be identified and addressed as early as possible to mitigate the burden of caregiving and for the betterment of the caregiver, care recipient, and professional care providers. Based on the study findings, formation of peer support groups among PCGs, counseling and psychotherapy at individual level and group level, provision of the correct information on right time including disease prognosis and information on available supportive care services, and referring the needy one to the correct services, and making available a booklet on childhood cancer caregiving for them during the early stage following diagnosis would help to reduce the distress among these caregivers, facilitating a better quality of life for the child and whole family.

ACKNOWLEDGMENT

I acknowledge all the study participants and experts in the clinical field, especially pediatric consultant oncologists at NCI, Maharagama, and the experts in the public health field who gave valuable inputs to complete the study successfully.

Declaration of interest:

All four authors declare that there is no conflict of interest in relation to this study.

REFERENCES

- [1] Santo, E. A. R. E., Gaíva, M.A.M., Espinosa, M.M., Barbosa, D.A., Belasco, A.G.S. (2011). Taking Care of Children With Cancer: Evaluation of the Caregivers' Burden and Quality of Life. *Rev. Latino-Am. Enfermagem*, 19(3):515-22.
- [2] Graneek, L., Rosenberg-Yunger, Z. R., Dix, D., Klaassen, R. J., Sung, L., Cairney, J., & Klassen, A. F. (2014). Caregiving, single parents and cumulative stresses when caring for a child with cancer. *Child Care Health Dev*, 40(2), 184-194. doi: 10.1111/cch.12008
- [3] Given, B. A., Given, C. W., & Sherwood, P. (2012). The Challenge of Quality Cancer Care for Family Caregivers. *Seminars in Oncology Nursing*, 28(4), 205-212.
- [4] Baidoobonso, S. (2014). Effect of supportive interventions on informal caregivers of people at the end of life. a rapid review. Toronto: Health Quality Ontario. Retrieved from: <http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/rapid-reviews>.
- [5] Gírgis, A., Lambert, S., Johnson, C., Waller, A., Currow, D. (2013). Physical, psychosocial, relationship, and economic burden of caring for people with cancer: A Review. *Journal Of Oncology Practice*, 9(4), 197-202.
- [6] Given, B. A., Given, C. W., & Sherwood, P. (2012). The Challenge of Quality Cancer Care for Family Caregivers. *Seminars in Oncology Nursing*, 28(4), 205-212.
- [7] Nympha, M. M. (2014). Psycho-educational Intervention for Caregivers of Head and Neck Cancer Patients: An experimental initiative from India. *IOSR Journal Of Humanities And Social Science (IOSR-JHSS)*, 19(4), 15-22.
- [8] Thomas, C., Morris, S., Soothill, K., McIlmurray, M., Francis, B., & Harman, J. (2001). What are the psychosocial needs of cancer patients and their main carers? A study of user experience of cancer services with particular reference to psychosocial need. Project Report. Lancaster University, Institute for Health Research
- [9] Wen, K. Y., & Gustafson, D. H. (2004). Needs assessment for cancer patients and their families. *Health and quality of life outcomes*, 2, 11. doi:10.1186/1477-7525-2-11
- [10] Sklenarova, H., Krümpelmann, A., Haun, M. W., Friederich, H.C., Huber, J., Thomas, M., ... Hartmann, M. (2015). When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*, 121(9), 1513-1519.
- [11] Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L., & Mood, D. W. (2010). Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. *CA: A Cancer Journal for Clinicians*, 60(5), 317-339.
- [12] Adler, N.E. & Page, A.E.K. (Eds.). (2008). *Cancer care for the whole patient: meeting psychosocial health needs*. Institute of Medicine [IOM]. Washington, DC: The National Academies Press.
- [13] Soothill, K., Morris, S. M., Harman, J. C., Francis, B., Thomas, C., & McIlmurray, M. B. (2001). Informal carers of cancer patients: What are their unmet psychosocial needs?. *Health and Social Care in the Community*, 9(6), 464-475.
- [14] Kerr, L. M. J., Con, C., Harrison, M. B., Medves, J., Tranmer, J. E., & Fitch, M. I. (2007). Understanding the Supportive Care Needs of Parents of Children With Cancer: An Approach to Local Needs Assessment. *Journal Of Paediatric Oncology Nursing*, 24(5), 279-293.
- [15] Dolgin, M. J., Phipps, S., Fairclough, D. L., Sahler, O. J., Askins, M., Noll, R. B., ... Katz, E. R. (2007). Trajectories of adjustment in mothers of children with newly diagnosed cancer: a natural history investigation. *J Pediatr Psychol*, 32(7), 771-782.
- [16] Hoekstra-Weebers, J. E. H. M., Jaspers, J. P., Kamps, W. A., & Klip, E. C. (2001). Psychological adaptation and social support of parents of pediatric cancer patients: A prospective longitudinal study. *Journal of Pediatric Psychology*, 26(4), 225-235.
- [17] Sawyer, M., Antoniou, G., Toogood, I., Rice, M., & Baghurst, P. (2000). Childhood cancer: a 4-year prospective study of the psychological adjustment of children and parents. *J Pediatr Hematol Oncol*, 22(3), 214-220.
- [18] Elcigil, A., & Conk, Z. (2010). Determining the Burden of Mothers with Children Who Have Cancer. *Dokuz Eylül Üniversitesi Hemşirelik Yüksekokulu Elektronik Dergisi*, 3(4), 175-181.
- [19] Aburn, G., & Gott, M. (2011). Education given to parents of children newly diagnosed with acute lymphoblastic Leukemia: A narrative review. *Journal of Pediatric Oncology Nursing*, 28(5), 300-305.
- [20] Yilmaz, M., & Ozsoy, S. (2009). Effectiveness of a discharge-planning program and home visits for meeting the physical care needs of children with cancer. *Supportive care in cancer. Official journal of the Multinational Association of Supportive Care in Cancer*, 18, 243-253.
- [21] Ringné, A., Jansson, L., & Graneheim, U. H. (2011). Parental experiences of information within pediatric oncology. *Journal of Pediatric Oncology Nursing*, 28(4), 244-251.

AUTHORS

First Author – Sachintha Dilhani W.N., MBBS, MSc in Community Medicine, MD in Community Medicine, National Cancer Control Program, Ministry of Health, Sri Lanka
navarathnasachi@gmail.com

Second Author – Sivayogan S., Emeritus Professor, Department of Community Medicine, Faculty of Medical Sciences, University of Sri Jayawardenapura, shivyom@yahoo.com

Third Author – Jayamal De Silva, Senior lecturer, Department of Psychiatry, Faculty of Medical Sciences, University of Sri Jayawardenapura, jayamalds@yahoo.com

Fourth Author - Suraj N. Perera, Consultant Community Physician, National Cancer Control Program, Ministry of Health, Sri Lanka,
pererasn@yahoo.com

Correspondence Author – Sachintha Dilhani W.N.
navarathnasachi@gmail.com