

Original Article

# Concerns of Primary Caregivers of Children with Complex Chronic Conditions in Kerala: A Qualitative Analysis

Sajida Abdulla<sup>1</sup>, Hariprasad Pallipurath Gopalakrishna Pillai<sup>1</sup>, Reshmi Ramachandran<sup>2</sup>

<sup>1</sup>Department of Pediatrics, Government Medical College, Ernakulam, Kerala, India, <sup>2</sup>Department of Community Medicine, Government Medical College, Ernakulam, Kerala, India.

## ABSTRACT

**Objectives:** Exploring data on primary caregiver experiences of dealing with chronically ill children (CIC) strengthens the ability of paediatricians to improve the quality of care by detecting unmet needs in paediatric palliative care and understanding their original concerns instead of presumed needs. Hence, this study aims to identify and describe the primary concerns and challenges faced by caregivers of children with complex chronic conditions in a tertiary care hospital in Kerala.

**Materials and Methods:** Primary caregivers of 25 children aged <13 years with non-malignant life-limiting illnesses, admitted to the paediatric department of a government medical college in Kerala between 1 July 2021 and 28 February 2022, underwent in-depth interviews to analyse their most worrisome issues. Thematic analysis was the method chosen for qualitative data analysis.

**Results:** The main themes identified were medical issues, unmet needs, caregiver health issues, and social and financial issues. Among the medical issues, poor seizure control and infected bedsores, sleep deprivation in both patient as well as caregivers, and difficulty in maintaining the personal hygiene of patients were the major issues. Parents of almost all the CICs reported that they required diapers more than any other material or device. Maternal depression was the major caregiver health issue. The unavailability of antiepileptic drugs in peripheral health centres resulted in missing doses and undue expenses for travel to tertiary centres to obtain the same. Caregivers reported their dismay when they finally realised that they were given false hopes of a cure by different systems of medicine.

**Conclusion:** The challenges faced by caregivers of children with complex chronic conditions are multifaceted. Their most problematic issues related to medical issues are the occurrence of breakthrough seizures and development of infected bedsores. The most important material hardship reported was diaper needs. Caregiver issues such as sleep deprivation and maternal depression must be identified and addressed while providing comprehensive palliative care.

**Keywords:** Paediatric, Palliative, Chronic illness, Caregiver, Concerns

## INTRODUCTION

The active total care of a child's body, mind, and spirit that includes supporting the family is known as palliative care for children.<sup>[1]</sup> Chronic illness affects 3.49% of children aged 0–14 in Kerala, South India.<sup>[2]</sup> Twenty-six percent of individuals in need have improved access to palliative care in Kerala, thanks to the 'Pain and Palliative Care Society' and neighborhood networks in palliative care, which provide local community-based care.<sup>[3]</sup> Data on caregiver issues of paediatric non-malignant palliative care are suboptimal, despite this remarkable advancement of palliative care in Kerala. Assessment of caregiver satisfaction related to communication and decision-making has been studied in

adults but hardly studied in children with complex chronic conditions who have multiple unmet needs for palliative care.<sup>[4]</sup> Complex chronic conditions are defined as 'any medical condition that can reasonably be expected to last at least 12 months (unless death intervenes) and involves either several different organ systems or one organ system severely enough to require specialty paediatric care and some period of hospitalisation in a tertiary care centre.'<sup>[5]</sup> Hospitalisation for palliative care is usually to decide on the management plans for intermittent crises, including sharing advanced decisions with the parents regarding interventions.<sup>[6]</sup> Given the unpredictability of their course, chronic illnesses in children can come with heavy physical,

\*Corresponding author: Sajida Abdulla, Department of Pediatrics, Government Medical College, Ernakulam, Kerala, India. [sajiabdulla@gmail.com](mailto:sajiabdulla@gmail.com)

Received: 14 January 2023 Accepted: 19 October 2023 Epub Ahead of Print: 04 January 2024 Published: 16 February 2024 DOI: 10.25259/IJPC\_9\_2023

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-Share Alike 4.0 License, which allows others to remix, transform, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

©2024 Published by Scientific Scholar on behalf of Indian Journal of Palliative Care

psychological, financial, and social consequences for both the patient and caregiver. Extrapolating adult palliative care data is inadequate because there are distinct patterns of paediatric life-threatening conditions.

Exploring data on primary caregiver experiences of dealing with chronically ill children (CIC) strengthens the ability of paediatricians to improve the quality of care by detecting unmet needs in paediatric palliative care and understanding their original concerns instead of presumed needs. Caregiver concerns may be strikingly different from what the paediatrician considers the first issue to be addressed in CIC. Such knowledge helps to avoid misunderstandings and frustration of parents while clinicians manage chronic illnesses. It also aids clinicians in creating realistic plans of care for these patients. Furthermore, potentially modifiable factors in the current health system can be identified and modified to improve comprehensive child and family care. Hence, there is a definite need to study the issues, unmet needs, and challenges faced by families of CIC.

This hospital-based study aims to identify and describe the most worrisome issues for the primary caregiver of a chronically ill child admitted to the paediatric ward of a government medical college in Kerala, South India.

## MATERIALS AND METHODS

SRQR guidelines were followed for conducting and reporting this research.<sup>[7]</sup> The research protocol was approved by the Institutional Research Committee and the Ethical Committee. Thematic analysis is the method chosen for qualitative data analysis in this study, as the aim was to describe caregiver experiences and explore their most problematic issues. The study population selected were parents of children aged <13 years with non-malignant life-limiting illnesses admitted to the paediatric department of a government medical college in Kerala between 1 July 2021 and 28 February 2022.

Those participants who could not speak the local language (Malayalam), those patients who had surgically correctable or medically curable conditions, or those who were recognised to be highly ill were excluded from this study.

Written informed consent was obtained from all the participants in the study before the interview [Appendix A]. After establishing a good rapport with the participants, in-depth interviews were conducted by the principal investigator during the study period with a conversational approach so that they could freely share their own experiences, issues, and needs. An interview guide was used for structuring the interview. The interview was conducted by the principal investigator in a private room in the hospital. Data collection included recording and transcribing the interviews into text. Field notes were also written during the interviews. The interview began with an open question: 'Can you tell me what worries you the most regarding your child?' More detailed responses were elicited by asking about their important

needs, physical, sleep, treatment, financial, drug availability, and family issues [Appendix B]. Interviews lasted an average of 1 hour. A consecutive sampling technique was used until data saturation was achieved. In the event of the caregiver having an emotional breakdown, the recording would be immediately stopped. The interviewer would provide them with empathetic support. These caregivers were referred to the psychiatrist and also received psychological counseling. Caregivers continued to have regular follow-ups with the psychology team, even after the discharge of the chronically ill child (CIC).

Information bias was planned to be minimised by audio recording during data collection. To prevent selection and information bias, the third author, who was not in direct contact with the participants, was involved in the process of identifying codes and extracting meaning units. The validity of this was confirmed by the other authors who cross-checked it. The first author translated the original text, which was in Malayalam, to English. The second author has been formally trained in paediatric palliative care. The third author is trained in qualitative research methodology.

## Methodological orientation

Initially, a 'meaning unit', which is words, sentences, or paragraphs containing aspects that answer the research question, was identified. The label of a meaning unit has been referred to as a 'Code'.<sup>[8]</sup> 'Themes' represent the overall concept on an interpretative latent level.<sup>[9]</sup> The 'codes' were identified from the transcripts as the most frequently repeated issues, and then, they were grouped into 'subthemes' based on similarities. Finally, the issues and needs were broadly classified as 'themes'. As there was marked heterogeneity of the chronic diseases and subthemes were finer in nature, data saturation was attained only after 24 interviews. It was at this point that the variety of issues faced by the caregivers was fully understood, and no further dimensions or insights could be found. Inductive approach of thematic analysis by Braun and Clarke was followed in this study.<sup>[10]</sup>

## RESULTS

As there were two CICs in one family, there were a total of 25 CICs. Among them, 14 were male (56%). Interviews were conducted with 24 primary caregivers. The interview was done with 15 mothers, eight fathers, and one paternal grandmother who were the primary caregivers of the CIC. The age group of patients with non-malignant life-limiting illnesses ranged from 9 months to 13 years of age. The baseline characteristics of the patients and their caregivers are given in Table 1.

The average age of mothers was 35 (standard deviation [SD]  $\pm 5.46$ ) and the average age of fathers was 41.8 (SD  $\pm 6.32$ ). The length of continuous hospital stay for the chronically ill child varied between 15 days and 350 days in a year [Table 2]. One mother had two children with life-limiting illnesses. By

**Table 1:** Baseline characteristics.

Major system involved	Chronic neurological illness (n=18)	Chronic kidney disease (n=1)	Chronic haematological illness (n=2)	Chronic respiratory illness (n=1)	Inborn errors of metabolism (n=3)
Age range (y)	1.5–12.5	12	8–11	10	0.75–12.5
Male: Female	12:6	Male	1:1	Female	1:2
Average age of mothers	27–45	36	36–40	38	28–45
Average age of fathers	32–55	45	45–48	48	35–55
Education of mother	Secondary school and above	Secondary school	Bachelor's degree	Secondary school	Secondary school
Average number of hospitalisations	5 admissions/year	24 admissions/year	12 admissions/year	8 admissions/year	3 admissions/year
Unemployed fathers n (%)	7 (38.8%)	1 (100%)	1 (50%)	1 (100%)	1 (33%)

**Table 2:** Major diagnosis, mean hospital stay and outcomes of the chronically ill children.

Participant ID (cases)	Major diagnosis	Mean hospital stay in a year	Outcome at the end of the study period
1, 2, 3, 11, 13, 15, 16, 20, 22	Spastic quadriplegia with complications	28 days	Alive
8, 9	Spinal muscular dystrophy	90 days	Case 9: Expired Case 8: Alive
19	Duchenne muscular dystrophy	15 days	Alive
1, 2, 4, 12, 13, 15, 16, 18, 21, 24	Refractory seizures with various underlying conditions	21 days	Alive
7	Subacute sclerosing pan encephalitis	75 days	Alive
25	Paraplegia-transverse myelitis/multiple brain abscess/ endophthalmitis left eye	350 days	Alive
5	Glutaric aciduria	60 days	Expired
6	Mucopolysaccharidosis	30 days	Alive
14	Severe aortic regurgitation	50 days	Expired
17	Cavitary tuberculosis	90 days	Expired
23	Combined oxidative phosphorylation deficiency (liver failure, neuroregression, blindness, and seizures)	168 days	Alive
10	End-stage renal disease/pulmonary oedema	36 days	Alive

ITP: Idiopathic thrombocytopenic purpura, ALL: Acute lymphocytic leukemia in remission

the end of the study period, 4 of the 25 CIC had succumbed to death. Twenty-two of the 25 (88%) who required recurrent and prolonged hospital-based palliative care were due to chronic neurological conditions.

Figure 1 illustrates the identified 'themes' of caregiver issues and needs. Sleep issues in caregivers and the CIC, poor seizure control, excessive oral secretions and infected bed sores in the CIC were the major medical concerns reported. It was observed that a 'diaper' was the crucial and universally necessary item, according to caretakers, for all CICs. Common codes identified are also included in Figure 1.

### Thematic analysis

The themes to be analysed were selected based on the answers to the primary question of what was the most problematic issue faced by the primary caregiver while taking care of a child with a life-limiting illness. The cardinal statements of the caregiver regarding their most worrisome issue and major subthemes are described below, in italics, to make

transparent the process from raw data to results.<sup>[11]</sup> Minor subthemes are described in Table 3.

### Medical issues of patients

#### Poor seizure control

According to the majority of the participants, poor seizure control was the primary concern.

*'While walking, he abruptly falls forward, hurting himself each time'* (case 2, mother of a 7-year-old boy).

Missing antiepileptic dosages happen because the tertiary hospital's 1-time supply of antiepileptic to a single patient is given for a maximum of 1 or 2 months at a time. Moreover, the unavailability of certain antiepileptic drugs from peripheral health centres also resulted in poor seizure control.

*I was unable to obtain her medication (antiepileptic) from our location. Whatever medication we got from here has been used up for a while. She is now experiencing prolonged seizures.* (Mother, case 4).

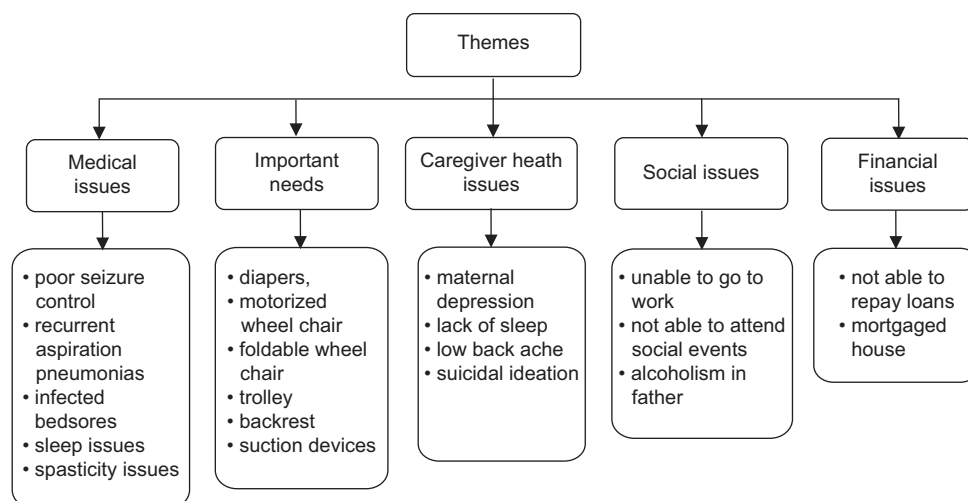


Figure 1: Major themes and subthemes.

Table 3: Minor subthemes and meaning units.

Subthemes	Meaning units
Poor sleep pattern in patient	'She gets up a hundred times during sleep' (case 5, mother of 2-year-old female)
Fear of the future of the child	'My main concern is who will take care of him once I pass away' (case 2, mother of a 2-year-old boy)
Failing to understand the child's pain	'I wish I could understand why he is crying. When he was younger, he could at least tell me where his pain was' (case 6, mother of a 12.5-year-old boy with neuroregression)
Procedural pain	'My child had suffered so much pain after they put the chest tubes' (case14, mother of a 10-year-old girl)

### Excessive oral secretions

'I keep wiping his face and neck and change his bibs all the time because it gets drenched with saliva, and if I get a little late, he smells very bad' (case 3, mother of a 1.5-year-old).

### Spasticity issues

'It is challenging for me to turn him by myself, but I know that unless I do, his bedsores won't heal' (case 1, mother of a 12.5-year-old obese male).

### Inability of self-care

Caregivers of older female CICs are concerned about managing menstruation. They were concerned about the inability of CICs to use menstrual pads by themselves. She used to dance very well. But now she can't even stand or walk. She even lost an eye... After all that she's been through (sighs), now, my worry is about how she will manage when she gets her periods. she cannot even feel the wetness of urine or blood. (Grandmother, case 25).

### Important needs

Parents of almost all the CIC reported that they required diapers more than any other material or device. They also said there is a very high requirement for diapers. Many participants expressed that if they could get a trolley on which they could clean and bathe the bedridden CIC, they would be able to provide better personal hygiene.

He needs about 13 packets of diapers every month. I spend around 6000 rupees for diapers alone in a month (Father, case 16).

### Caregiver health issues

Eleven mothers were on antidepressants (45%). Lack of sleep and resultant fatigue was the most common health issue reported by the participants.

I have been on treatment for depression since 2 months of his birth (Mother, case 2).

### Sleep deprivation among caregivers

'Since his birth, I have not been able to get more than two hours of uninterrupted sleep' (case 3, mother of a 1.5-year-old male).

### Suicidal thoughts in the primary caregiver

'I had already made the decision to terminate my life when he was little' (case 11, mother of a 12-year-old boy).

### Socio Economic issues

#### Delay in obtaining funds

Delay in obtaining funds and delay in the paperwork needed for renal transplantation resulted in at least two admissions in 1 week for a child with the end-stage renal disease with recurrent pulmonary oedema.

We are running around for money for his kidney transplantation. All we want is the papers to be ready as soon as possible (Father, case 23).

### **Lack of awareness of palliative care facilities**

Some families drive far distances just to change feeding tubes because they are unaware of local palliative care providers.

*In our place, we do not know of any palliative care nurse who can come to our home to change her feeding tube* (Mother, case 5).

### **Financial constraints**

Twelve families were under the burden of bank loans (48%). Debts were incurred mainly for the treatment of the CIC.

*They said he would be able to walk, so I had to take bank loans repeatedly to pay for his treatment. I once even prayed that he better die after my wife doused herself in kerosene. To live and let him live, I took bank loan again, bringing my total debt to ten lakh rupees* (Father, case 22).

### **Late referral**

'I regret that we brought her here so late. They could have referred her before she became so sick' (case 17, mother of a 9-month-old female).

### **False hopes**

'We believed him (Dr X) when he said there is a cure for my child. Now we know we are giving her good care even if we cannot cure her' (case 7, father of 4-year-old girl).

### **Loss of job**

'How can he go to work when we have two children with SMA' (cases 8, 9; mother of a 6-year boy and 10-year-old girl).

## **DISCUSSION**

Children with chronic critical illnesses are reported to have five times longer hospital stays than other patients.<sup>[12]</sup> According to Higginson *et al.*, hospital-based palliative care teams improve care for patients and families.<sup>[13]</sup> Neurological illness is the major system involved in our group of CIC. Fuhrer reported a similar pattern in CIC (75%).<sup>[14]</sup> Severe refractory epilepsy, as defined by Kwan and Brodie, is associated with a high risk of mortality and morbidity, including sudden unexplained deaths.<sup>[15]</sup> The lack of availability of antiepileptic drugs in the peripheral health centres causes a significant financial drain since they have to travel to tertiary care centres to procure the same. If these drugs were made available in the peripheral health units as part of the Rashtriya Kishor Swasthya Karyakram by the National Health Mission, this would help reduce the out-of-pocket expense and indirect cost incurred for travel.

Excessive oral secretion is a main concern for many caregivers, which is often not considered an important issue by some paediatricians. The sudden onset of prolific respiratory secretions at the time of death or 'death rattle' can be controlled well with morphine, especially in neurogenic pulmonary oedema.<sup>[16]</sup> End-of-life care

challenges were not included in the interview guide. End-of-life care was offered to three children (cases 5, 9, 17). However, it could not be given to one child who suddenly deteriorated (case 14). This mother's main worry was the pain her child underwent after two intercostal drainage insertions. Pain prevention and control is another important issue that should be addressed from the intensive care unit itself and continued till the very end of life. Reflective open-ended questions help to optimise treatment by the palliative care team after aligning with the care goals of the patient and caregivers.<sup>[17]</sup>

Parental need to engage with children and the need to listen to them is recommended for normal children,<sup>[18]</sup> but our study participants (cases 6 and 15) revealed that they felt despair when they could not communicate with their children. Cases 7 and 17 experienced a great deal of confusion, emotional stress, and financial loss due to contradictory opinions given by different systems of medicine regarding the cure of the disease. False hopes contributed to their depression. Treating units can use the language of the right hope to promote patient welfare without denying the facts to the caregivers of the patients.<sup>[19]</sup> False hopes can be avoided by providing facts about the nature of illness and the effectiveness of various end-of-life care plans. Caregivers of CIC expressed relief on the discontinuation of futile treatments and on the provision of meaningful hopes.

Parents of cases 1, 6, 8, and 23 revealed a feeling of unease when the subject of an eventual transfer to adult care was brought up, which is consistent with Menon J *et al.* findings.<sup>[20]</sup> Significant psychological issues in both children and their parents have been reported due to the increased financial burdens due to the loss of jobs, especially in pandemic situations.<sup>[21]</sup> A system to access the available government funding without delay would mitigate these caregivers' distress, as Govindaraj *et al.* suggested in a similar setting with a different group of paediatric patients.<sup>[22]</sup>

Paediatricians often presume that the most important requirements of children with chronic illness (especially those with chronic neurological illness) are equipment such as cerebral palsy chairs, callipers, or orthoses.<sup>[23]</sup> Contrary to such presumptions, this study reveals that the majority of them needed 'diapers'. The purchase of diapers accounts for a significant expense for the chronically ill child. Provisions for free-of-cost diapers through the government or NGOs will help tackle this major concern shared by the caregivers in the present study.

Sleep issues in both parents and the chronically ill child are another significant problem that is not usually addressed during routine rounds by paediatricians. Increased nighttime awakenings were reported in our study subjects. This finding is similar to the study of Hysing *et al.*<sup>[24]</sup> Caregiver depression and fatigue were found in those participants whose sleep was

disrupted due to nighttime care. Chronic sleep deprivation in the caregivers negatively affects the care of CIC.<sup>[24]</sup> Adequate rest for these mothers at home will be possible through the establishment of palliative day care centres at the peripheral level with community participation and involvement of local self-government.<sup>[25]</sup>

Advice to mothers of spastic quadriplegic children to frequently change their position to prevent bedsores is not going to be effective or practical unless the rest of the family members or palliative care staff lend the mother/primary caregivers a helping hand in doing this, particularly in the case of obese children. Networking of various governmental and non-governmental palliative care centres would boost the services provided to the chronically ill and their families.<sup>[26]</sup> Nursing interventions such as changing feeding tubes, urinary catheters, and dressing bedsores can be coordinated with such service providers. The treating paediatricians should contact local palliative care providers before discharging these in-patients so that continuum of care can be maintained.

## CONCLUSION

The challenges faced by caregivers of children with complex chronic conditions are multifaceted. Their most worrisome issues related to medical issues are the occurrence of breakthrough seizures and development of infected bedsores. The most important material hardship reported was diaper need. Caregiver issues such as sleep deprivation and maternal depression must be identified and addressed while providing comprehensive palliative care.

## Acknowledgements

The authors are indebted to Dr. Bifina Beegum, Assistant Professor, Paediatrics for the help extended for cross-checking the translations of the quotes of caregivers.

## Ethical approval

The authors declare that they have taken the Institutional Ethics Committee approval and the approval number is IEC-84/2021.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

## Financial support and sponsorship

Nil.

## Conflicts of Interest

There are no conflicts of interest.

## Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the

writing or editing of the manuscript and no images were manipulated using AI.

## REFERENCES

- Craig F, Abu-Saad Huijjer H, Benini F, Kuttner L, Wood C, Feraris PC, *et al.* IMPaCCT: Standards of Paediatric Palliative Care. *Schmerz* 2008;22:401-8.
- Krishnaswamy P. Kerala Research Program on Local Level Development. In: Neelakantan S, Nair PR, Shaji H, editors. *Morbidity Study-Incidence, Prevalence, Consequences and Associates*. Thiruvananthapuram: Centre for Development Studies; 2004. p. 17-59.
- Manoj R. Care in the Community. The Hindu Weekend Edition 2020. Available from: <https://www.thehindu.com> [Last accessed on 2022 Apr 25].
- Dhiliwal SR, Ghoshal A, Dighe MP, Damani A, Deodhar J, Chandorkar S, *et al.* Development of a Model of Home-based Cancer Palliative Care Services in Mumbai-Analysis of Real-world Research Data Over 5 Years. *Indian J Palliat Care* 2022;28:360-90.
- Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric Complex Chronic Conditions Classification System Version 2: Updated for ICD-10 and Complex Medical Technology Dependence and Transplantation. *BMC Pediatr* 2014;14:199.
- Emanuel LL, Librach SL. *Palliative Care E-book: Core Skills and Clinical Competencies*. 2<sup>nd</sup> ed. Philadelphia, PA: Saunders; 2011. p. 562-69.
- Dossett LA, Kaji AH, Cochran A. SRQR and COREQ Reporting Guidelines for Qualitative Studies. *JAMA Surg* 2021;156:875-6.
- Ansari M, Rassouli M, Akbari ME, Abbaszadeh A, Akbari Sari A. Educational Needs on Palliative Care for Cancer Patients in Iran: A SWOT Analysis. *Int J Community Based Nurs Midwifery* 2018;6:111-24.
- Graneheim UH, Lundman B. Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness. *Nurse Educ Today* 2004;24:105-12.
- Braun V, Clarke V. Using Thematic Analysis in Psychology. *Qual Res Psychol* 2006;3:77-101.
- Bengtsson M. How to Plan and Perform a Qualitative Study Using Content Analysis. *Nursing Plus Open* 2016;2:8-14.
- Shappley RK, Noles DL, Spentzas T. Pediatric Chronic Critical Illness: Validation, Prevalence, and Impact in a Children's Hospital. *Pediatr Crit Care Med* 2021;22:e636-9.
- Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AG, *et al.* Do Hospital-based Palliative Teams Improve Care for Patients or Families at the End of Life? *J Pain Symptom Manage* 2002;23:96-106.
- Fuhrer M. Neurological Palliative Care in Children. *J Neurol Sci* 2017;381:10-5.
- Kwan P, Brodie MJ. Definition of Refractory Epilepsy: Defining the Indefinable? *Lancet Neurol* 2010;9:27-9.
- Macleod AD. Neurogenic pulmonary edema in palliative care. *J Pain Symptom Manage* 2002;23:154-6.
- Rome RB, Luminas HH, Bourgeois DA, Blais CM. The Role of Palliative Care at the End of Life. *Ochsner J* 2011;1:348-52.
- Sekaran VC, Ashok L, Kamath VG, Kamath A, Hegde AP, Devaramane V. Parental Involvement-Perceptions of Parents and their Adolescent Children. *Indian J Pediatr* 2020;87:200-6.
- Garrard E, Wrigley A. Hope and Terminal Illness: False Hope Versus Absolute Hope. *Clin Ethics* 2009;4:38-43.
- Menon J, Peter AM, Nayaar L, Kannankulangara A. Need and Feasibility of a Transition Clinic for Adolescents with Chronic Illness: A Qualitative Study. *Indian J Pediatr* 2020;87:421-6.
- Saurabh K, Ranjan S. Compliance and Psychological Impact of Quarantine in Children and Adolescents due to Covid-19 Pandemic. *Indian J Pediatr* 2020;87:532-6.
- Govindaraj GM, Ramya U, Raj R, Athulya EP, Jain A, Scaria V, *et al.* Parental Experience of Hematopoietic Stem Cell Transplantation for Children with Primary Immune Deficiency Disorders. *Indian J Pediatr* 2021; 88:370-1.
- Gowda VK. Recent Advances in Cerebral Palsy. *Karnataka Paediatr J* 2020;35:4-18.
- Hysing M, Siversten B, Stormark KM, Elgen I, Lundervold AJ. Sleep in Children with Chronic Illness, and the Relation to Emotional and Behavioral Problems-A Population-Based Study. *J Pediatr Psychol* 2009;34:665-70.

25. Meltzer LJ, Mindell JA. Impact of a Child's Chronic Illness on Maternal Sleep and Day Time Functioning. *Arch Intern Med* 2006;166:1749-55.
26. Deenadayalan SK, Veerajah S, Elangovan V, Sathyamurthy K. Status of Palliative Care Services in Tamil Nadu-A Descriptive Report. *Indian J Palliat Care* 2022;28:413-8.

**How to cite this article:** Abdulla S, Gopalakrishna Pillai HP, Ramachandran R. Concerns of Primary Caregivers of Children with Complex Chronic Conditions in Kerala: A Qualitative Analysis. *Indian J Palliat Care*. 2024;30:47-55. doi: 10.25259/IJPC\_9\_2023

## APPENDICES

### APPENDIX A

#### Consent form

Title of the Study: Concerns of primary caregivers of children with complex chronic conditions in Kerala - A qualitative analysis

Principal Investigator: Dr Sajida Abdulla, Assistant Professor, Department of Paediatrics, GMC Ernakulam, Kochi, Kerala, India. E-mail: sajiabdulla@gmail.com. Phone:9400164513.

Co-investigators: Dr. P. G. Hariprasad, Associate Professor, Department of Paediatrics, GMC Ernakulam. Dr. Reshmi Ramachandran, Assistant Professor, Community Medicine Ernakulam.

I,....., parent of....., wholeheartedly give my consent to take part in the study done by Dr Sajida Abdulla, Dr PG Hariprasad, Dr Reshmi Ramachandran, titled as 'Concerns of primary caregivers of children with complex chronic conditions in Kerala - A qualitative analysis.'

I understand that participation in this study is voluntary and I can withdraw at any time without giving reason and that this will not affect the treatment of my child in any manner. The data collected from my interview will be documented and audio recorded. I wholeheartedly give my consent for audio recording of my interview. I understand that during the interview, the principal investigator will sit down with me in a comfortable place at the hospital. If I do not wish to answer any of the questions during the interview, I understand that I may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless I would like someone else to be there. The information recorded is confidential, and no one else will have access to the information documented during my interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. The tape will be kept confidentially in a separate folder with password known only to the principal investigator. The information recorded is confidential, and no one else will have access to the tapes. The tapes will be destroyed after 4 weeks of recording. There is a risk that I may share some personal or confidential information by chance, or that I may feel uncomfortable talking about some of the topics. However, the investigators do not wish for this to happen. I understand that I do not have to answer any question or take part in the interview if I feel the question(s) are too personal or if talking about them makes me uncomfortable. There will be no direct benefit to me but my participation is likely to help the researchers find out more about how to prevent difficulties which children suffering from complex chronic illnesses in our community.

I understand that I will not have to bear any expenses for participating in this study. I understand fully all the clauses mentioned above.

Signed by

Mother/Father/Guardian

Dated

Place

### APPENDIX B

#### Qualitative interview guide

1. Participant ID number:
2. Age of child:
3. Sex of child:
4. Primary caregiver: Mother/Father/Other
5. Age of father:           Age of mother:
6. Phone number:
7. Educational qualification of father:  
Educational qualification of mother:
8. Occupation of father:       Occupation of mother:
9. Socioeconomic class: Upper/Upper middle/Lower middle/  
Upper lower/Lower
10. Present complete diagnosis:

#### Questionnaire

- Q1. Can you tell me what worries you the most regarding your child?
- Q2. What do you understand about the illness of your child?
- Q3. How satisfied are you regarding the treatment received by your child?
- Q4. How many times did your child get admitted to the hospital last year?
- Q5. How often does your child need Outpatient department consultation?
- Q6. How do you travel to reach our medical college hospital?
- Q7. Around how many days did you have to take leave from your job due to your child's illness in the last year?
- Q8. Did you ever have to leave a job due to the child's illness?
- Q9. How are you managing the child's treatment expenses?
- Q10. What help/devices did you receive from other sources like the government/NGO?
- Q11. Which material/device do you think your child needs the most?
- Q12. Could you tell me which medical issue of your child's illness is most bothersome to you?
- Q13. Do you think your child is having relief from his pain/other symptoms
- Q14. Does your baby sleep well? How often does he get up?
- Q15. Do you have any medical issues? Are you on any medications?
- Q16. How long do you sleep at a stretch?



- Q17. Have you found the health staff to be cooperative and understanding?
- Q18. From where do you procure medicines ? Do you have any issues ?
- Q19. How supportive is your spouse? Does she/he help with the child's care?
- Q20. Is your spouse alcoholic
- Q21. Does anyone blame the mother for child's illness?
- Q22. Have you ever felt low or hopeless?
- Q23. Have you thought about suicide anytime?
- Q24. What gives you strength to move on?