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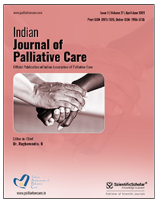

Original Article

The Challenges, Coping Mechanisms, and the Needs of the In-hospital Parents Caring for Children with Life-limiting Neurological Disorders: A Qualitative Study

Fahisham Taib[1], Khoo Teik Beng[2], Lee Chee Chan[2]

[1]Department of Paediatrics, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan, Malaysia, [2]Department of Paediatrics, Hospital Tunku Azizah, Kuala Lumpur, Malaysia.

ABSTRACT

Objectives: Parents who have children with complex lifelong and life-limiting neurological conditions experienced many stresses and anxieties throughout their lives as caregivers. However, this information is still very limited. The study aimed to explore the challenges faced by parents with children who have complex neurological conditions, their coping strategies, needs, and expectations.

Materials and Methods: A semi-structured, in-depth interviews were conducted in the either Malay or English language among the parents of children with complex lifelong neurological conditions and have been on long-term in-patient hospital care. The interviews were audio-recorded and transcribed for thematic analysis. The qualitative study was conducted from October to November 2016 at the Paediatric Institute of Hospital Kuala Lumpur. Grounded theory was used to examine the qualitative data with inductive and deductive types of coding. The transcripts were read repeatedly to allow familiarity to the themes presented by the participants. Further discussions were conducted among the researchers to triangulate the information.

Results: A total of 11 parents were interviewed for this study. The thematic analysis resulted in 8 challenges: Physical wellbeing, Environment, Relationship, Financial, Occupational, Rational, Mental, and Spiritual. Coping strategies comprised problem focused issues related to the key challenges in the caregivers' context. Similar to the needs and expectations, the key themes were derived from the key understandings of the challenges and looking at the palliative care impacts for these children.

Conclusion: There are various challenges faced by parents of children with life-limiting neurological disorders. Physical, Environment, Relationship, Financial, Occupational, Rational, Mental, and Spiritual Wellbeing can be a platform for the assessment of the caregivers' needs and the planning for palliative care support.

Keywords: Challenges, Coping, Need, Paediatric palliative care, Neurology

INTRODUCTION

Parents usually found themselves caring for their children who are ill, disabled with chronic and life-limiting neurological illnesses. Therefore, their well-being as caregivers is important to ensure the continuity of care. Primary caregivers are those who are largely involved in giving assistance to any activities related to communication, daily care, housework, transport, and medical assistance.[1] Due to the complexity of care, with the intention of managing patients at home, many of the caregiving skills must be acquired by the primary caregivers, in our context, the parents. These caregiving tasks have been carried out by the family members continuously, traversing unfamiliar territories such as simple psychological support and nursing skills. The caregivers' well-being are multi-faceted and multi-layered concepts, hence the need to account for multiple components[2] and the long-term effects of caring for a patient physically, cognitively, socially, and emotionally.

There are many challenges faced by the caregivers, from treatment uncertainty, being an informal health-care provider, financial difficulties, minimal social support, treatment abandonment, emotional exhaustion, and among others.[3] Caregivers suffered from vanishing control over their lives due to exacerbation of their own health issues and stresses. There are significant unmet needs which could negatively have impacted the caregivers. The relationship

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*__Corresponding author:__ Lee Chee Chan, Department of Paediatrics, Hospital Tunku Azizah, Kuala Lumpur. leecheechan@gmail.com

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between caregivers' coping ability and emotional experiences is complex. Coping is the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person.[4] Having effective coping mechanisms may be one of the most important predictors of well-being across the life span. Coping is used to modify stressor and how one feels about the stressor. Various coping patterns have been identified, including confrontation, distancing, self-controlling, seeking social support, accepting responsibilities, escape-avoidance, problem solving, positive re-appraisal, and rediscovering life meaning.[5]

The needs of parents caring for children with neurological conditions are different from the informal caregivers for adult and for different types of illnesses. Their needs depend on the trajectory of the disease, requiring one to understand the uniqueness of the needs and rapidly changing physical, emotional, social, cognitive, and spiritual development.[6] Their medical and social needs shift as the disease progress and death occurs. Other factors are rarity of the disease, response of the family members and uncertain treatment modalities on what is best for the patient. Although, the findings have somehow been established in the previous studies, there is paucity of local data on caregivers caring for their life limiting neurological children.

The objectives of this study are to investigate the challenges, coping mechanisms and the needs of the parents of paediatric patients with neurological conditions. Appropriate recommendations and supports would be needed consistent with the concept of paediatric palliative care.

MATERIALS AND METHODS

This was an exploratory qualitative study which was designed to explore the breadth of the issues related to the challenges, coping styles, and needs of caregivers of children with neurological conditions. Data collection was done through semi-structured interview.

Study site

The study was conducted at the Paediatric Institute wards, Hospital Kuala Lumpur, which was the largest tertiary paediatric hospital in Malaysia, at the time of study. The institute is a 138-bedded paediatric hospital, and function as the national referral centre for the complex medical cases in various medical and surgical fields.

Participants of the study

Parents of 11 patients were interviewed voluntarily from the October 1, 2016, until November 31, 2016. The in-depth interviews were audio-recorded and transcribed from the language that was communicated.

Sampling method

A purposive sampling was used to recruit the study participants. Parents of children with neurological illnesses, who have been in the wards for longer than 2 weeks were included in the study. These were children who required a complex medical management involving various multi-disciplinary teams. Parents were approached for voluntary participation and informed consent was taken prior to the interview. The reason for choosing this group was because of the length of the hospital stays was longer than those with other medical conditions. Exclusion criteria include parental refusal for the interview.

In-depth interviews were utilized and facilitated by the third author (LCC) who has no direct connection and influence on the parents. These interviews were guided by the newly developed interview protocol. The interview guide was formulated by the researchers based on the research questions [Table 1]. Interview was done either in Malay or English language, according to the participants' preference.

Data storage, analysis, and interpretation

The first and third author (FT, LCC) read the transcripts repeatedly to familiarize and identify the key issues. The

Table 1: Interview protocol for in-depth interview with the parent.

Part A: Introduction	• Researcher (s) introduced themselves • Thanking participants for their involvement in the study
Part B: Main and Probing questions	Challenges • How has your life changed after having a child with this illness, as compared to before? • Can you tell me the problems you faced in day-to-day life while your child is admitted to the ward? • Out of the problems described, can you rank them in the order from most distressing/important to the least distressing/important? • What kind of feeling do you experience for yourself or for your child while your child is admitted? Coping • How do you cope with the difficulties and stress you or your child faced while in the ward? • What information that you wish to get from the medical staff every day? Needs and expectations • What help do you need the most in taking care of your child in the ward? • What suggestions do you have for us to improve our services to you and your child?
Conclusion	• Asking participants to share inputs that were excluded in the conversation

Table 2: Thematic analysis covering the challenges, coping and needs or expectation.

Theme	**Subtheme**		
	Domain		
	Challenges	**Coping**	**Needs/Expectation**
Physical wellbeing	1. Inadequate sleep 2. Night feeding/suction 3. Back pain 4. Infection transmission	1. Work through with spouse 2. Take rest when child was sleeping 3. Help from other family members	1. Help to carry patient 2. Respite when I take shower 3. Feeding machine as in hospital usage
Environmental/ Equipment	5. Admission and registration 6. Bed 7. Parking 8. Toilet 9. Temperature 10. Food/Entertainment 11. Disturbance 12. Phone line/Internet 13. Travelling	4. Low expectation (Acceptance) 5. Priority (Care quality) 6. Get support from Disability Living Allowance	4. Feeding pump at night 5. Equipment for mobility and transfer 6. Toilet bigger, clean, dry 7. Flexible registration 8. Option for room and bed 9. Parking lots 10. On time feeding/medication
Relationship/Social wellbeing	14. Focus fully on patient 15. Relationship with spouse 16. Care for other children 17. Family members' involvement 18. Family social activities 19. Communication with PICU staff	7. Keep simple life 8. Exercise after settling the patient 9. Learn to keep silence when having different opinion with spouse 10. New friendship with other parents and volunteers in ward 11. Keep friends' support 12. Not to involve neighbour (to avoid critic) 13. Talks to spouse and family first 14. Work through with staff 15. Being more understanding	11. Supports from spouse and family members 12. Friendly and supportive relationship with staff 13. Need honest, up-to-date information 14. Want their concerns being heard 15. Explanation for other family members
Financial wellbeing	20. Stress on financial issues 21. Need money for transport, formula milk, phone bills, diapers 22. No financial issue	16. Cut down expenses, cook mainly at home 17. Need to work extra jobs 18. Work at home 19. Sell properties	16. Money for milk, diapers, transport
Occupational wellbeing	23. Frequent emergency leave 24. Frequent unpaid leave 25. Work accumulates	20. Work out with spouse 21. Single parent care 22. Work at home/hospital	17. Flexible working time
Rational/Intellectual wellbeing	26. Learning for home feeding, suction, medication, physiotherapy 27. Time management 28. Medical information 29. Decision making (e.g. tracheostomy)	23. Role setting with spouse 24. Only handle priority of care 25. Details planning before trip 26. Be more independent 27. Bring patient along to work 28. Learn from experience 29. Get information online 30. Compliance to all doctor's advice	18. Getting experience and training from medical team 19. Actively being a part of team 20. Improve parenting and time management skills
Mental/Emotional wellbeing	30. Worry 31. Boring 32. Sad 33. Lonely 34. Suicidal thought 35. Stressful to leave patient 36. Fluctuation of conditions 37. Guilty	31. Relax 32. Think positive 33. Cry 34. Stay strong 35. Acceptance, believe in God 36. Reduce expectation 37. Focus on work	21. Medical information 22. Need reassurance about their care technique 23. Respite when I pray 24. Emergency care plan

(Contd...)

Table 2: *(Continued).*

Theme	Subtheme		
	Domain		
	Challenges	**Coping**	**Needs/Expectation**
Spiritual/Attitude well being	38. Uncertainty 39. Uncontrollable 40. Self-Value (confidence) 41. Meaning in life 42. Forgiveness 43. Judgement	38. Believe in God (things will be better) 39. Acceptance (less expectation) 40. Search for alternative treatment (hope) 41. New meaning (patient) 42. Live in presence, stop thinking 43. Relax and be thankful	25. Information about the prognosis and how to maintain hope 26. Need more time for praying 27. Best interest discussion with staff

data were then coded and undergone thematic analysis for grouping, accordingly. Connections within and between themes were identified for interpretation. Another author (KTB) read the transcripts for peer checking. Conflicting ideas were jointly discussed, and analysis was utilized to clarify interpretations for consensus.

Ethical approval

Written informed consents were attained from the participants. The study was approved by the Institute for Clinical Research Malaysia (NMRR-15-2460-24627).

RESULTS

Seven fathers and four mothers agreed to be interviewed. Most of them were Malay (n = 9), one each from Chinese and Indian ethnics, respectively. The age children's age ranges between 4 months and 13 years. For the neurological diagnosis, 3 of them had structural abnormality, 2 with epileptic syndrome, spinal muscular atrophy, and syndromic children, and 1 each for congenital infection and kernicterus. From the result of the study, we have developed mnemonic Physical, Environment, Relationship, Financial, Occupational, Rational, Mental, and Spiritual Wellbeing ("PERFORMS") to simplify the findings [Table 2]. Under each theme, the challenges, coping strategies, needs, and expectations from the parental perspective are described.

Physical well-being

Four subthemes have been extracted from the challenges describing themes such as inadequate sleep, night feeding/suction, back pain, and concern on the infection transmission.

- Since he (my child) came out of intensive care unit (ICU), I have never slept at home. He (my husband) was the only one who goes home (P1)
- When I was in private (hospital), usually the nurses do (all) the care, but here (in the government hospital), I must do all the care (alone) (P2)
- I am worried when she has a cough, and the milk comes out from her nose. I fear she will have breathing issue (P3)
- He is now getting bigger, and (I am) unable to lift him up anymore. I also have sickness (P5).

Participants identified their coping strategies by working with their spouses, getting adequate rest, and getting help from other family members. This arises from the participants' understanding on the limitations of their physical needs, such as getting help to carry the patient, adequate respite care as well as the needs for available supporting machines like those used in the hospital.

- Getting into High Dependency Ward (now) is better, at least there is help and support such as physio (P1)
- I hope for improvement. I don't think he will be the same as he was previously (P3).

Environmental/equipment well-being

For challenges under this theme, participants recognized that there were several environmental, social, and amenities deficiencies. They pointed out the difficulties in admission and registration, in securing available bed for elective stay, limited parking spaces, sharing toilet with other caregivers, poor environmental temperature control, limited choice of food, and entertainment while on the ward, lack of privacy, lack of internet access, and transportation issues.

- The room is small, and the bed is too short (for me to lie down) (P1)
- My child's mouth was dry. I ask (the nurses) for "Vaseline" but it did not come until my husband bring it over (from home) (P3).

In terms of coping mechanism, some participants stated that they had to accept the less ideal situation that they were in as long as the quality of care was maintained. The parents also preferred to prioritize helps that they received and trying to acquire financial assistance from the government disability living allowance. They were aware of the basic environmental needs such as the availability of feeding pump for night use, equipment for mobility and transfer, infrastructure such as redesigning house for better toilet access, having a flexible access to the hospital, having the option to choose available room and bed for hospital admission, providing better parking lots and, feeding and medication administration on schedule for their children.

- If my child going to sleep, he needs me to accompany him (P5).

Relationship/social well-being

Under this theme, the challenges for the participants were the need to fully focus on patient's care, ensure a harmonized relationship with their spouse, ensure adequate care for other children, obtain help and support from extended family members, proactively organized family's social activities and ensure a healthy communication with the paediatric ICU (PICU) staffs.

- Iman (My child) does not like that doctor… I don't like her, she is "noisy" (P1)
- She (mother) loves Rayyan very much (compared to father) (P6).

They coped by keeping their lives simple, doing exercises after settling their sick children, learning on how to tolerate with their spouse, starting new friendship with other parents and actively volunteering in the ward to maintain friends' support. They stated their disfavour involving their neighbours for support but preferred to communicate directly with their spouse and family first, working with the medical staffs and learn to understand more through their experience. Among the needs discovered were the need for support from the spouse and family members, the need for a friendlier and more supportive relationship with staffs, the need for an honest and up-to-date information, the need to get their concerns heard and appropriate explanation for all the family members.

- Father will give whatever she wants… (P1)
- I have to settle all other problems with the brother and sister before coming to hospital (P3).

Financial well-being

Challenges in the financial dimension emerged as these parents have to go through the financial hardship to accommodate the needs of their child. The identified financial needs were the cost of daily care and nutritional support such as the cost of transportation to the hospital, purchasing formula milk, paying phone bills and diapers. Their coping strategy was by cutting off their basic expenses, changing and adapting to new lifestyles such as cooking mainly at home rather than dining out, engaging extra jobs from home and some even had to sell off their properties to cover their living expenses. Those who do not have regular jobs usually had no issue in bringing their children over for clinical review, but those who have regular jobs need to take time off for clinical appointments.

- A lot of work pending and work accumulated. There is no helper (at work) and…. I have to complete the work (P6)
- When I want to go for umrah (in Mecca), many things that comes into my mind…. Who will give his "food", who is going to care (for) him (P5)
- There's a lot of problem…. We have to sell the (our) car (P4).

Occupational well-being

Occupational challenges include frequent emergency leave, unpaid leave, and work accumulation due to work absences. They coped by planning and sharing works with their spouse, ensuring one parent act as the caregiver or being creative by working from home or hospital. They often lamented to having a more flexible working time.

- If my child is discharged home, I will take the leave and let my husband work (P1).

Rational/intellectual well-being

The challenges pertaining to this theme include learning the basic nursing skills such as home feeding, suction, medication, physiotherapy, managing time well, adequate medical information, and appropriate assistance in decision making. Some of the coping ways were role setting with their spouse, prioritizing daily care, making details planning before any trip, trying to be more independent, bringing patient along to work, learning from experience, getting adequate information online, and ensuring compliance to doctor's advice. Some of the needs mentioned were getting experience and training from the medical team, trying to be an active member of the team, and improving parenting skills and time management skills.

- My only expectation is when my child can go home… that means she is healthy now. (P6)
- I want to know how to use BiPAP machine, its setting, correct technique for physio (P6)
- The nurse asked me to register and leave the child alone to register (somewhere else)… I have to go alone while awaiting for my husband…. (P2)
- I prefer doctor who tell me directly… Straight to the point…. We understand well and accept what will happen (P7).

Mental/emotional well-being

In the mental challenges faced by the participants, there were non-exhaustive lists including different emotional reactions to the experience such as being worried, boring, sadness, lonely, having suicidal thoughts, unwillingness to leave patient to be cared by others, emotional fluctuation, and guilt. They coped by taking time off, thinking out loud positively, crying in seclusion, preferring to stay strong, accepting the current situation, reducing their own expectations, and focusing on their daily work. The needs discovered were the needs for medical information, reassurance about their care techniques, respite care, and support for emergency care plan.

- If I am stressed at work, I will share my story with my colleague…. For support. I do not reveal with my siblings (P1)
- When he was first diagnosed, I was very worried… if he stopped breathing (P2)
- I always am worried… worried because many of his "peers" has passed on (P5).

Spiritual/attitude well-being

Spiritual challenges experienced by these caregivers include the feeling of uncertainty, uncontrollable, self-value, finding the meaning in life, forgiveness, and not being judgmental. Among the coping styles for spiritual context were believing in God, accepting their predicament, searching for alternative treatment, finding new meaning of their experiences, living in presence, stop thinking and be grateful of what they already have. The needs in spiritual dimension were on information of the disease prognostication and maintaining hope, adding more time for praying, and best interest discussion regarding their children.

- We have to accept whatever the decision made by God…. If we hope that he (Rayyan) to be healthy…. Even he cannot manage himself …. Giving us "new" Rayyan (P6)
- I can pray now to God, have support from friends and staffs… I believe in doctor, and I believe in God (P6)
- Death is God's business; Living also God's business…. I accept everything… but when it happened (to you), I could feel the strain (P6).

DISCUSSION

This was the first attempt to study the issues among the in-patient caregivers of children with complex neurological conditions in Malaysia. We aimed to explore the impact of caregiving of the neurologically ill children among parents who have stayed in the hospital for a long period of time. Conceptually, the research was not intended to create new concept but searching for practical values parallel to the local setting. This was achieved by investigating the different themes using qualitative study analysis, looking at the similarities and differences of the challenges, coping styles and needs. Several key findings have been observed using PERFORMS mnemonic that covers most of the expected themes. Understanding these key issues are vital for the caregivers to shape a better understanding on the aspect of managing these children holistically. Caring for the neurologically ill patients can be stressful and putting strains on the family in many domains. The impact is multi-faceted involving familial, personal, and even community sphere.[7]

Well-being is a condition of a system in which the essential qualities are relatively stable or a state of equilibrium or balance that can be affected by life events or challenges.[8] Each element of well-being varied individually based on their experiences, knowledge, cultures, and the disease trajectories of their children. Most of the evidence was taken from caregivers of patients with cancer or under palliative care support. Caregivers must face changes in their family circumstances which could potentially impact their health, financial, and social well-being. The prevalence of stress, anxiety, and insomnia is high among the caregivers, which could also lead to mortality and morbidity.[1] We found 8 dimensions of well-being that could be expressed – Physical, Emotional, Relationship, Financial, Occupational, Rational, Mental, and Spiritual. Intricate to the challenges in our context, even minimal coping strategies have been employed depending on the needs of the patients or the expectations of the caregivers.

People cope with changes and challenges that would dynamically affect their well-being. In cancer study, caregiver's burden encompasses the difficulties of the caregiver's role and the associated alterations in the caregiver's emotional and physical health that can occur when care demands exceed resources.[9] Significant distress was associated with watching patient's clinical deterioration and with the reduction in cognitive ability and physical dysfunction. There were overlapping features of connectedness with emotional, occupational, relationship, and spiritual well-being. Caregivers would resort to variety of coping strategies which include distractive strategies, internalization of the burden, and disengagement from stressful thoughts.[6] However, coping styles may shift as treatment and disease change, and previous coping styles did not necessarily impact the level of distress later. There is also evidence that coping styles can act as a buffer for depression in cancer caregivers.[9]

Coping strategies include the cognitive and behavioural efforts required to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person.[10] In a study in children with disability, 3 coping styles have been implemented – problem focused, active emotion and avoidant emotion. The former 2 strategies were associated with good quality of life (QOL).[9] It was also documented that caregivers who searched for information, sought for social support, appropriate self-care, and understood the patient's neurological conditions, affect the outcome and QOL.[10,11] This is confirmed through the systematic review that adaptive coping strategies may be positively associated with psychological QOL among caregivers of children with chronic illness.[12] Another study also sought to explore caregivers' perceived coping and different support mechanisms. They found 7 key themes - finding a support person; finding the right support person; surviving the high workload; seeking alternative means of support; juggling home and work difficulties; potentially failing to cope; and disillusionment versus acceptance in finding a support person.[13] Although themes were labeled differently and focused mainly on support, the message remained similar, covering the aspect that we suggested in our mnemonic PERFORMS.

Sound knowledge and understanding of the requirements for these patients, with activities and family support, are the well-being enhancer for the caregivers toward a better outcome, clinically, and psychologically.[14] Filial obligation is a cultural norm in Malaysia, whereby family members are socially and morally obliged to care for their unwell family members. Without respite care, it is difficult to quantify the caregivers' burden individually and moreover in the developing world, this has become a highly subjective matter due to filial responsibility. These caregivers will become 'invisible patients' as they also have needs as a result of their experience caring for these complex patients. They need to be resilient and could withstand stress which is shaped by baseline characteristics, evolving states, and psychosocial outcomes. This is a critical component of psychological care.[15] Resilience evolved over time as a result of coping styles, hope, and level of support. Our study highlighted different expectations in various domains. Therefore, individualized supportive care model for the parents should be based on the assessment, with the aim of optimizing the elements of well-being as suggested in our mnemonics.

There are few limitations in our study. First, only 11 parents agreed to participate. We were unable to collect a larger number of parents needed for further analysis of the qualitative study. Second, there were only a limited number of complex neurological conditions cases during the study period. And thirdly, we were unable to explore issues related to diverse ethnic group due to the limited number of parents from different cultural background at the time of study.

CONCLUSION

The challenges, needs and coping strategies by parents who have children with neurological conditions could be simplified in PERFORMS mnemonic. Health-care professionals should be aware of the interconnectedness between these factors as they may affect the well-being of these caregivers. Target interventions are needed to avoid the burnout and poor mental, physical, and social well-being among these caregivers.

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Declaration of patient consent

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

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Conflicts of interest

There are no conflicts of interest.

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