

# Prevalence of the Unmet Needs and its Predictors among Working Mothers of Children with Epilepsy Attending Specialist Hospitals in Kelantan

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## ABSTRACT

**INTRODUCTION:** Unmet needs arise when everyday assistance is lacking. Epilepsy's unpredictability creates significant work-family conflict for working women, potentially leading to increased unmet needs. This study aimed to determine the prevalence and the factors related with the unmet needs of working mothers with children with epilepsy (CWE) in Kelantan. **MATERIALS AND METHODS:** A cross-sectional study using the validated Malay version of the Family Needs Survey questionnaire was conducted among 204 working mothers aged 18 to 60 of CWE attending specialist hospitals in Kelantan. Data were analysed using descriptive statistics and multiple linear regression. **RESULTS:** The highest unmet need was for community services (81.6%), followed by information (71.9%), social support (53.1%), financial (43.2%), explaining to others (28.9%), and family functioning (28.4%). Having follow-ups at tertiary hospitals reduced the unmet need score for information ( $B=-0.669$ , 95%CI= $-1.276,0.081$ ,  $p=0.021$ ) and social support ( $B=-1.454$ , 95%CI= $-2.225, -0.683$ ,  $p<0.001$ ). Living in nuclear types of family reduced the unmet need score for community services ( $B=-0.669$ , 95%CI= $-1.276,0.081$ ,  $p=0.021$ ) and information ( $B=-1.216$ , 95%CI= $-1.965,-0.466$ ,  $p=0.002$ ). Working in the government sector increased the unmet need score for social support ( $B=0.437$ , 95%CI= $0.062, 1.454$ ,  $p=0.033$ ). Full-time employment ( $B=-0.761$ , 95%CI= $-1.244,-0.279$ ,  $p=0.002$ ) reduced the unmet need score for family functioning. Contract employment status ( $B=0.566$ , 95%CI= $0.074,1.058$ ,  $p=0.024$ ) increased the unmet need score for family functioning. **CONCLUSION:** Mothers of CWE working in the government sector, under contract employment, and seeking follow-up care in secondary hospitals were related to higher unmet needs. The study findings may assist policymakers in introducing a child-friendly employment policy and flexible working arrangements among working parents of children with chronic illnesses such as epilepsy.

## Keywords

Epilepsy, Unmet Needs, Working Mothers, Children.

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## INTRODUCTION

Epilepsy is a neurological disorder characterized by and the availability of antiepileptic drugs, a substantial recurrent, unprovoked seizures stemming from abnormal portion of patients, including children, remain untreated.<sup>4,5</sup> brain activity, with broad implications encompassing biological, psychological, and social dimensions.<sup>1</sup> It poses The impact of epilepsy on children is significant; affecting a significant global health challenge impacting millions their physical, cognitive and psychosocial development.<sup>5</sup> worldwide, yet a considerable portion of these patients Children with epilepsy (CWE) often experience learning particularly in low- and middle-income countries, lacks difficulties, social stigma and reduced quality of life.<sup>6</sup> The access to effective treatment.<sup>2,3</sup> Children, notably during associated comorbidities and the long-term consequences their first year, are susceptible to epilepsy, and while of the condition further compound the global burden of profoundly affects them, research in this area remains epilepsy on children.<sup>7</sup> limited.<sup>4</sup> Despite advances in understanding the disease

In addition to the direct impact on children, epilepsy also places a significant burden on their caregivers. Families of CWE face numerous challenges, including financial strain, social isolation and emotional distress.<sup>8-10</sup> Caregivers often experience high levels of stress, anxiety, and depression, which can negatively impact their own health and well-being.<sup>11</sup> They have a range of unmet needs that can hinder their ability to provide optimal care for their children. These unmet needs are multifaceted, encompassing informational<sup>12,13</sup>, emotional, financial<sup>14</sup>, social<sup>8-10</sup>, and family functioning aspects.<sup>15</sup>

Mothers, in particular, are often primarily responsible for caring for CWE. They are likelier to be the primary caregivers and face unique challenges in balancing their caregiving roles with other responsibilities, such as employment and household duties.<sup>6,16,17</sup> The demands of caring for a child with epilepsy can lead to increased stress, reduced work productivity, and strained family relationships.<sup>18</sup>

In Malaysia, despite improvements in epilepsy management and treatment, support for caregivers remains limited, with a lack of comprehensive support services such as counselling, respite care and educational resources. This gap in care is particularly challenging for working mothers. Various factors, such as lower socioeconomic status, lower educational levels, high seizure frequency, a high number of antiepileptic medications, having more sick children, being a single mother and employment characteristics, have been shown to impact caregivers' quality of life and contribute to unmet needs.<sup>19-21</sup>

In Malaysia, the increasing number of working mothers in recent years has further highlighted the challenges faced by those with caregiving responsibilities for CWE.<sup>22</sup> Working mothers often struggle to balance their professional and caregiving roles, leading to increased stress and burnout.<sup>23,24</sup> They may face difficulties finding appropriate childcare, managing work schedules, and accessing support services catering to their needs.<sup>22,25</sup> To our knowledge, although there were abundant research which focused on parents with chronic disease children, there is hardly any study among working mothers.

To address this issue, the first research study in Kelantan is being conducted to determine the prevalence and the factors associated with the unmet needs of working mothers with CWE. By understanding these mothers' unique challenges, the study aims to contribute actionable insights that may inform more inclusive and effective healthcare and social support, ultimately enhancing the quality of life for both CWE and their dedicated caregivers. While this study focuses on working mothers, it serves as a starting point for future research to explore the experiences of diverse caregivers and develop comprehensive support strategies that cater to the needs of all those involved in the care of CWE.

## **MATERIAL AND METHODS**

### **Study Design and Participants**

This cross-sectional study was conducted in Kelantan over four-month period from February until August 2023. The study participants were recruited from all government hospitals with specialists in Kelantan. The inclusion criteria were biological working mothers (18 to 60 years old) of CWE aged 18 years old and below registered at Pediatric Neurology Clinics in Kelantan. Working mothers who were diagnosed with chronic mental illnesses and non-Malaysians were excluded.

The sample size was calculated using a single proportion formula. The estimated sample needed was 219 participants using 5% type 1 error, 57.5% proportion, and an additional 10 % missing data.<sup>13</sup> There were 200 working mothers with CWE registered at the Pediatric Neurology Clinic in Kelantan. All eligible mothers were selected.

### **Research Tool and Data Collection**

Data were collected using a self-administered proforma and the Malay version of the Family Needs Survey (FNS) questionnaire. The proforma consists of working mothers' sociodemographic characteristics, employment details, and children's characteristics. The FNS was initially developed by Donald B. Bailey and Rune J. Simeonsson to assess the needs of families with handicapped children.<sup>46</sup> Subsequently, the FNS was translated and validated in Malay version.<sup>14</sup> It consists of 35 items across

six subscales: information, social support, community services, explaining to others, financial support, and family functioning. Respondents who answered 0 (Not applicable), 1 (I definitely do not need help with this) or 2 (Not sure) were given a score '0' while respondents who answered 3 (I definitely need help with this) in the questionnaire were given score '1'. The minimum possible score is 0, the maximum possible score is 35. A higher score indicates higher unmet needs. Respondents rated each item from 0 to 3, indicating their need for help. Unmet needs were calculated by summing the items rated as '3'. Scores ranged from 0 to 35, with higher scores indicating more unmet needs.

### Statistical Analysis

SPSS Statistics (IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp) was used for data entry and analysis. The proportion of the unmet needs, the socio-demographic characteristics of working mothers and CWEs, and the employment characteristics were presented using mean, standard deviation (SD), frequency, and percentage. The predictors were analyzed using simple and multiple linear regression. Statistical significance was defined as a p-value <0.05.

## RESULTS

### Characteristics of Participants

Based on the study findings (Table I, Table II, Table III), most mothers were Malay (96.1%), married (97.5%), belonged to nuclear families (79.4%) and Muslims (96.1%). Most had attained higher education (93.2%) and had less than one child with chronic illness. Regarding employment characteristics, 76% of the mothers were engaged in full-time employment, and 63.7% held formal employment. Most worked at specific workplaces (71.6%) and had permanent job status (80.4%). About half of the mothers adhered to office hours (52.9%), and nearly half were employed in the government sector (48.5%). The CWE had a mean age of diagnosis of 3.05 (SD 2.84) years. Over a third of the children were registered with social welfare services (35.8%), and 15.7% had other comorbid

## Operational Definition

The operational definition is as follows:

Working mother	Defined as a mother who engages in paid work, either full-time or part-time
Unmet needs	Needs or assistance from others to perform everyday activities is not provided or is inadequate. In this study, the unmet needs among working mothers of CWE were assessed using the Malay version of the FNS questionnaire and in-depth interviews. This questionnaire's scores range from 0 to 35; higher
A child with epilepsy	A child below the age of eighteen years diagnosed with
Full time	The total number of working hours is between 32 to 40 hours per week. <sup>28</sup>
Part-time	The total number of working hours is under 32 hours per week. <sup>29</sup>
Formal worker	Formal working agreement between employers and employees. An employee usually: <ul style="list-style-type: none"> <li>• Wear professional attire</li> <li>• Keep regular working hours</li> <li>• Work in the same place every day</li> <li>• Earn a regular salary or hourly wage</li> </ul>
Informal worker	There is no formal working agreement between employers and employees. Employers may change their employees' compensation, hours, and work environments.
Permanent jobs	Persons whose main job is a work contract of unlimited duration or regular workers whose contract lasts 12 months or over. <sup>31</sup>
Contract jobs	Workers whose main job is a fixed-term contract lasting up to one year, occasional, casual, or seasonal work, or work lasting less than 12 months. <sup>31</sup>
Government sector	All government-owned or government-affiliated organisations, including the federal government, states, and
Private sector	They are owned and managed by private individuals or enterprises, taking risks to create jobs and generate a profit. They are competitive, and they have the incentive to be efficient.

conditions. On average, each child took 2.35 (SD 2.19) prescribed drugs and had a seizure frequency of 4.45(SD 15.86) times per month.

**Table I:** Sociodemographic characteristics of working mothers of CWE, n= 204

Variables	Mean (SD)	Frequency (%)
Age (year)	38.68 (6.43)	
Distance hospital from house (km)	29.42 (42.05)	
Race		
Malay		196(96.1)
Non-Malay		8 (4.0)
Marital Status		
Married		199 (97.5)
Divorced		5 (2.5)
Family Type		
Mixed		42 (20.6)
Nuclear		162 (79.4)
Religion		
Islam		196 (96.1)
Other*		8 (4.0)
Number of children in house	2.9 (1.31)	
Education level		
Basic education		14(6.8)
Higher education		190 (93.2)
Chronic disease		
No		187 (91.7)
Yes		17 (8.3)
Own transport		
Yes		178 (87.3)
No		26 (12.7)
Number of children that has chronic disease (Excluding Patient)	0.15 (0.39)	

**Table II:** Employment characteristics of working mothers of CWE, n= 204

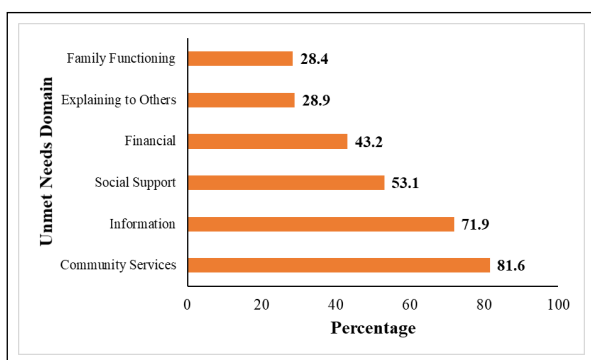
Variables	Mean (SD)	Frequency (%)
Types of employment		
Full time		155 (76.0)
Part-time		49 (24.0)
Work Formality		
Formal		130 (63.7)
Informal		74 (36.3)
Location of works		
Specific workplace		146 (71.6)
Work from home		58 (28.4)
Job status		
Permanent		164 (80.4)
Contract		40 (19.6)
Salary		
Monthly		145 (71.1)
Non-monthly		59 (28.9)
Employment Schedule		
Office Hour		108 (52.9)
Non-office hour		96 (47.4)
Work sector		
Government		99 (48.5)
Non-Government		105 (51.5)

**Table III:** Sociodemographic characteristics of CWE, n= 204

Variables	Mean (SD)	Frequency (%)
Age (year)	7.38 (4.34)	
Gender		
Male		117 (57.4)
Female		87 (42.6)
Age of diagnosis (year)	3.05 (2.84)	
Registered with JKM		
Yes		73 (35.8)
No		129 (63.2)
Other Comorbid		
Yes		32 (15.7)
No		172 (84.3)
Number of drugs	2.35 (2.19)	
Seizure frequency	4.45 (15.86)	
Hospital follow-up		
Tertiary centre		148 (72.5)
Secondary centre		56 (27.5)
Experienced adverse drug reaction		
No		172 (84.3)
Yes		33 (16.2)

### The Prevalence of the Unmet Needs

The Family Needs Survey questionnaire comprised of six domains. The highest prevalence of unmet needs was observed in the Community Services domain (81.6%), followed by information domain (71.9%), social support domain (53.1%), financial domain (43.2%), and explaining to others domain (28.9%). The lowest unmet need was observed for the family functioning domain (28.4%). Result is shown in Figure 1.



**Figure 1.** The prevalence of the unmet needs of working mother of CWE (n= 204)

### Factors Related to the Unmet Needs among Working Mothers of CWE

Multiple regression analysis revealed several factors significantly related to the unmet needs scores across domains for working mothers of children with epilepsy (CWE). Mothers whose children received tertiary hospital follow-up and those from nuclear families had lower unmet information needs while having children with comorbidities and maternal illness increased information needs. Having follow-ups at tertiary hospitals reduces,

while working in the government sector increases, the unmet social support needs. Nuclear family status lowered unmet community service needs. Having children with comorbidities increases unmet financial support needs. Full-time work reduces, while contract work and having children with more frequent seizures increase unmet family functioning needs. Greater distance from home to the hospital, having children with comorbidities, and having children with more frequent seizures increased unmet family functioning needs. Greater distance from home to the hospital, having children with comorbidities, and having male children increased unmet needs in explaining the condition to others.

### DISCUSSION

#### The prevalence of Unmet Needs among Working Mothers of CWE

The Family Needs Survey (FNS) questionnaire provides valuable insights into the challenges faced by working mothers of children with epilepsy (CWE) highlighting diverse challenges across multiple domains. Addressing these unmet needs is a critical issue that requires attention. There is a scarcity of a global research specifically focused on this topic.

Our study showed the highest prevalence of unmet needs was on community services. The findings revealed that 86.8% of mothers struggled to obtain appropriate care for their CWE, while 83.3% encountered difficulties locating a suitable preschool. This indicates a shortage of specialized healthcare services or a lack of awareness about existing

**Table IV:** Factors related with the unmet needs among working mothers of CWE in Kelantan by simple and multiple linear regression (n = 204).

Variables	Crude b <sup>a</sup> (95% CI)	p-Value	Adjusted b <sup>b</sup> (95% CI)	t-Stat	p-Value	R <sup>2</sup>
<b>UNMET NEEDS FOR INFORMATION</b>						
<b>Types of hospital follow-up</b>						
Secondary	1		1			
Tertiary	-1.405 (-2.120, 0.690)	<0.001	-0.883 (-1.599, -0.167)	-2.432	0.016	
<b>Child's Comorbid</b>						
No	1		1			
Yes	1.664 (0.785, 2.544)	<0.001	1.459 (0.609, 2.309)	3.386	0.001	0.211
<b>Type of Family</b>						
Mixed	1		1			
Nuclear	-1.036 (-1.841, 0.231)	0.012	-1.216 (-1.965, -0.466)	-3.197	0.002	
<b>Mother's Illness</b>						
No	1		1			
Yes	1.695 (0.522, 2.868)	0.005	1.901 (0.745, 3.057)	3.244	0.001	
<b>UNMET NEEDS FOR SOCIAL SUPPORT</b>						
<b>Types of hospital follow-up</b>						
Secondary	1		1			
Tertiary	-1.600 (-2.377, 0.823)	<0.001	-1.454 (-2.225, -0.683)	-3.723	<0.001	
<b>Work's Institution</b>						
Non-Government	1		1			0.116
Government	0.437 (-0.282, 1.156)	0.233	0.758 (0.062, 1.454)	2.148	0.033	
<b>UNMET NEEDS FOR COMMUNITY SERVICES</b>						
<b>Types of family</b>						
Mixed	1		1			
Nuclear	-0.669 (-1.257, 0.081)	0.026	-0.690 (-1.276, -0.104)	-2.323	0.021	0.038
<b>UNMET NEEDS FOR FINANCIAL</b>						
<b>Child Comorbid</b>						
No	1		1			
Yes	1.076 (0.323, 1.828)	0.005	1.073 (0.318, 1.828)	2.803	0.006	0.038
<b>UNMET NEEDS OF FAMILY FUNCTIONING</b>						
<b>Types of employment</b>						
Part-time	1		1			
Full time	0.208 (-0.272, 0.687)	0.394	-0.761 (-1.244, -0.279)	-3.111	0.002	
<b>Job-status</b>						
Permanent	1		1			0.106
Contract	0.545 (0.033, 1.056)	0.037	0.566 (0.074, 1.058)	2.269	0.024	
<b>Seizure Frequency</b>						
Frequency	0.018 (0.006, 0.031)	0.005	0.019 (0.007, 0.032)	3.114	0.002	
<b>UNMET NEEDS EXPLAINING TO OTHERS</b>						
<b>Distance house to the hospital</b>						
Distance house to the hospital	0.008 (0.002, 0.014)	0.010	0.008 (0.002, 0.013)	2.607	0.010	
<b>Child Comorbid</b>						
No	1		1			0.102
Yes	0.766 (0.024, 1.509)	0.022	1.439 (0.562, 2.316)	3.234	0.001	
<b>Gender</b>						
Girl	1		1			
Boy	0.577 (0.070, 1.085)	0.026	0.614 (0.124, 1.104)	2.469	0.014	

<sup>a</sup>Simple linear regression

<sup>b</sup>Multiple linear regression

Stepwise/backward/forward multiple linear regression is applied; model assumptions are fulfilled; no interactions among independent variables are observed, and no multicollinearity is detected.

resources. This is particularly concerning, as CWE often requires ongoing medical management, including regular check-ups, medication adjustments, and monitoring for potential side effects or complications.<sup>32</sup> Without access to appropriate care, these children may be at risk of suboptimal seizure control, developmental delays and reduced quality of life.<sup>33</sup> However, our research highlights the importance of addressing these challenges and the need for supportive community services for working

mothers with caregiving responsibilities, particularly those caring for CWE.<sup>9</sup> In Malaysia, the Facebook Malaysian Society of Epilepsy is a support group that helped to spread awareness about the illness and provide a platform for parents and children to share experiences and learn from each other.<sup>34</sup> In Malaysia however, no specific community services are available for working mothers. Previous research by Berger & Font (2015) demonstrated the positive impact of community services on the well-

being of families with children with chronic conditions, emphasizing the need for tailored interventions to bridge this gap.<sup>35</sup> Additionally, in the United States, community organizations such as the Epilepsy Foundation and the National Association of Epilepsy Centers offer various support programs and resources for individuals and families affected by epilepsy, which can be beneficial for addressing these needs.<sup>36</sup>

The prevalence of unmet information needs was 71.9%, with the most pressing issues being lack of information about their child's condition or disability (82.4%) and insufficient knowledge about the child's growth and development (80.9%) which reflected inadequate information. The information needs of parents of children with epilepsy is a critical aspect of caregiving. Several studies have shed light on the specific requirements and gaps in knowledge that parents experience. A systematic review study conducted by Nevin et al (2020) reported limited availability of detailed information and the need for clear realistic information.<sup>37</sup> Therefore, these caregiving parents had elevated stress levels, diminished psychosocial well-being, and decreased satisfaction with healthcare services. It was supported by the findings reported by Jain et al (2018) who emphasized the pivotal role of accessible information in empowering parents of CWE. Ali Maher Nashaat et al (2022) demonstrated the effectiveness of intervention programs in improving mothers' knowledge, attitude, and practice of epilepsy, directly addressing the unmet information needs and challenges faced by these mothers. This result emphasized the necessity of developing targeted informational resources to address the specific concerns of working mothers with CWE, aligning with recommendations from the *Epilepsy Foundation* (2015).

The prevalence of unmet needs of social support at 53.1% echoes the findings of a meta-analysis by Jones et al (2019), illustrating the pervasive challenges in establishing a supportive network for families affected by epilepsy.<sup>41</sup> The most pressing issues identified were the lack of time to communicate with the child's teacher or therapist (69.1%) and the absence of a family member to discuss problems with (63.2%). These results highlight the

importance of addressing the social support needs of these mothers to promote better outcomes for both the child and the family. In Malaysia, the Malaysian Epilepsy Society works to improve the lives of individuals with epilepsy. They bring together medical professionals, caregivers and patients, including those with epilepsy, family members, doctors, nurses, healthcare workers, researchers and volunteers. Meetings provide a space to share experiences, learn about epilepsy and raise public awareness. The goal is to inspire everyone to collaborate for the betterment of people with epilepsy.<sup>42</sup> Additionally, the study revealed that family resilience and social support play mediating roles in the relationship between illness severity and depressive symptoms among primary caregivers of children with epilepsy, highlighting their significance in mitigating the negative impact of epilepsy severity on caregivers' mental health.<sup>43</sup>

The prevalence of unmet needs in financial support (43.2%) and explaining to others (28.9%) is consistent with the studies on the economic burden and societal misconceptions surrounding epilepsy.<sup>47,48</sup> In the financial domain, the primary areas of concern were paying for essential expenses such as food (59.8%) and accessing more counseling or assistance in securing employment (46.1%). A meta-synthesis of qualitative research studies highlighted the economic challenges caregivers face, including the need to be available to monitor the child, interrupting their career development and increased economic burden due to long-term care and medication needs.<sup>44</sup> Additionally, studies have highlighted the association between financial burden and maternal stress, anxiety and depressive symptoms.<sup>45,46</sup> Furthermore, the financial burden experienced by mothers of CWE has been linked to lower quality of life and increased parenting stress.<sup>18</sup> Currently, in Malaysia, a diagnosis of epilepsy alone does not guarantee eligibility for welfare assistance despite the significant financial and caregiving burden associated with the condition. This issue is not unique to epilepsy, as a large number of parents of children with various disabilities have reported similar challenges in obtaining necessary support.<sup>47</sup> This underscores the critical need for financial support to alleviate the economic strain on these mothers and improve their overall well-being.

Apart from financial assistance, CWE mothers also face difficulties articulating their child's condition to others. The decision to disclose a child's epilepsy diagnosis can be a source of stress and anxiety for parents, and they may face difficulties in navigating the disclosure decision-making process.<sup>48</sup> Furthermore, community perceptions of developmental and behavioral problems experienced by children with epilepsy can contribute to the stigma and challenges faced by mothers in explaining their child's condition to others.<sup>49</sup> This highlights the need for support and resources to help mothers effectively communicate and educate others about epilepsy, thereby reducing stigma and promoting understanding and acceptance.

The reported unmet need in family functioning is noteworthy, highlighting the broader impact on the family unit. This domain is a significant concern, as indicated by several studies. A study by Reilly et al (2018) found that mothers of children with epilepsy experience unmet expectations of the child, feel rejected by the child, or have not adequately bonded with the child, indicating specific areas of family functioning that are affected.<sup>50</sup> Other studies also emphasized the higher prevalence of disruption of family functioning among mothers of children with autism spectrum disorder (ASD), which is consistent with the challenges faced by mothers of children with epilepsy.<sup>51</sup> Additionally, stress levels are often high in caregivers of patients with chronic diseases such as epilepsy, leading to lower parent-child relationship quality and problems with family functioning.<sup>51</sup> Therefore, clinicians should be aware of the impact of epilepsy on maternal psychosocial outcomes and family life.<sup>52</sup> Family-centered care interventions should be considered in addressing these challenges and promoting resilience within the family structure.

### **Factors Related with the Unmet Needs among Working Mother of CWE**

We found that working mothers who belonged to a nuclear type of family had lesser unmet needs as compared to those who belonged to an extended type of family. This finding showed the impact of extended family structure on communication patterns and decision-making dynamics. Cultural norms and stigma may hinder open discussion of the child's epilepsy within

extended families. Mothers may face challenges accessing information due to larger family involvement and unclear role expectations.<sup>34</sup>

Our study also showed that having follow-ups at tertiary hospitals reduced the unmet need for information and social support. Specialized epilepsy clinics in tertiary hospitals provide comprehensive care from multidisciplinary teams, contributing to improved patient outcomes compared to secondary hospitals which have limited expertise. However, disparities exist globally regarding access to specialized care.<sup>35</sup> Communication gaps at secondary hospitals may contribute to unmet informational needs for parents.<sup>36,37</sup>

In our study, the presence of comorbidities in children with epilepsy was found to increase mothers' unmet need for information, explaining to others and financial costs. Managing comorbid health conditions in children with epilepsy places significant demands on parents. Factors such as treatment complexity, time constraints, financial costs, limited access to information and social support can heighten unmet needs for working mothers.<sup>38,39</sup>

Our study revealed that mothers working in government sector had higher unmet need for social support as compared to those working in non-government sector. Government work environments may have different policies, structures and levels of flexibility when compared to the private sectors. Public sector jobs may have more inflexible schedules and limited options for remote work, making it difficult for mothers to balance work and caregiving responsibilities.<sup>40</sup> This is further complicated by the unique considerations in diagnosing, working up, and managing pediatric epilepsy. Resource constraints in government sectors also limit family-friendly policies and caregiver support programs.<sup>40</sup> Research indicates that workplace flexibility, including working from home and part-time employment, can positively impact parent-child interactions, especially for mothers.<sup>49</sup>

Being a contract worker intensified the unmet need of the working mothers as reported in our study. This finding could be related to job insecurity. Job insecurity is

recognized as a critical factor influencing the well-being of employees, especially in the context of caregiving responsibilities. Contract employment may elevate anxiety about employment stability for these mothers, as highlighted by Piccoli et al (2021) leading to increased stress and anxiety.<sup>41</sup> Anxiety due to lack of job security experienced by working mothers with caregiving responsibilities may have significant implications on their family life. Research has shown that mothers who were the primary caregivers experienced increased stress and anxiety about the stability of their employment, which can impact their overall well-being and family dynamics.<sup>42</sup> Overall, contract employment can contribute to job insecurity, limited benefits, work schedule inflexibility and family planning uncertainty for working mothers. This can exacerbate challenges in balancing caregiving and work demands.<sup>43</sup>

Our research found that mothers who had a male child diagnosed with epilepsy had higher unmet need for explaining to others as compared to those having a female child. There were societal stereotypes or misconceptions about epilepsy, and these was found to be more pronounced when the affected individual is a boy. Research has shown that societal stereotypes and misconceptions about epilepsy can lead to stigma and discrimination, impacting the well-being of individuals with epilepsy and their families.<sup>45</sup> Lack of understanding and misconceptions about epilepsy can contribute to social isolation and a sense of exclusion, particularly for families dealing with the condition. Therefore, addressing these stereotypes and misconceptions through increased awareness and education is essential to support families dealing with epilepsy and to promote understanding and empathy within the community.

## CONCLUSION

In conclusion, our study findings underscore the pressing need for a holistic and multidimensional approach to support working mothers of CWE. Community services, targeted information dissemination, social support programs, financial interventions, and awareness campaigns emerge as key components of an effective strategy. Policymakers and healthcare providers may

formulate comprehensive strategies to address the unique needs of this vulnerable population by integrating our study findings into evidence-based frameworks and interventions documented in existing literatures. Moreover, further research and initiatives are needed to better understand and meet the specific community service needs of this population.

## INSTITUTIONAL REVIEW BOARD (ETHIC COMMITTEE)

Ethics approval was obtained from the Medical Review and Ethical Committee from National Institute of Health, Ministry of Health Malaysia [NMRR ID-23-00180-QCH (IIR)] and Research and Ethics Committee, Universiti Sains Malaysia [USM/JEPeM/ KK/23010067].

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