THE UNMET NEEDS AMONG WORKING MOTHERS OF CHILDREN WITH EPILEPSY ATTENDING SPECIALIST HOSPITALS IN KELANTAN: A MIXED METHODS STUDY

NOOR AIDA BINTI ABDULLAH

UNIVERSITI SAINS MALAYSIA

2024

THE UNMET NEEDS AMONG WORKING MOTHERS OF CHILDREN WITH EPILEPSY ATTENDING SPECIALIST HOSPITALS IN KELANTAN: A MIXED METHODS STUDY

by

NOOR AIDA BINTI ABDULLAH

Thesis submitted in fulfillment of the requirements
for the degree of Doctor of Public Health (Family Health)

June 2024

ACKNOWLEDGEMENT

Bismillahirahmanirrahim.

In the name of Allah, the Most Compassionate, the Most Merciful. Praise to Allah s.w.t., who has eased my journey with His divine guidance, making each step more bearable and purposeful. Special appreciation is extended to those who played pivotal roles in completing my Doctor of Public Health (DrPH) research.

My heartfelt thanks go to my supervisors, Dr. Raishan Shafini binti Bakar, Associate Professor Dr. Azriani Ab Rahman, and Dr. Surianti Sukeri from the Department of Community Medicine, School of Medical Sciences, Universiti Sains Malaysia. I am forever indebted to them for invaluable guidance; each uttered word reflects the depth of their wisdom in the field. Their meticulous approach and constant support greatly influenced the course of my research. I am deeply thankful to my field supervisor, Dr. Nor Azni bin Yahaya, a neurologist from Pediatric Unit Hospital Raja Perempuan Zainab II, for his unwavering support and guidance. In moments of uncertainty, his expertise lit the path forward. All of them have tirelessly helped me from the initial stages to the completion of this study.

I am thankful to the Malaysian Ministry of Health for facilitating the data collection process. Appreciation goes to the working mothers of CWE in Kelantan who participated in the study and generously offered their time amidst busy schedules.

I extend my thanks to the knowledgeable lecturers who generously shared their expertise throughout the DrPH program, providing me with a robust foundation. Sincere appreciation also goes to my colleagues, especially the girls (Nur Azlina, Nur Dalilah, Saidah Adilah, Nur Sujaihah, and Sarah Aqilah). Their words of encouragement had been a lifeline during challenging moments. The continuous exchange of updates, insightful discussions, and generosity in sharing knowledge have made the academic pursuit less difficult and enjoyable.

I am forever indebted to my family for their unwavering love, support, and sacrifices throughout this incredible academic journey. To my parents, Abdullah bin Harun and Siti Ara binti Mohd Nor, words cannot express my profound gratitude for your constant encouragement, unconditional love, and invaluable life lessons that have shaped me into the person I am today. Your belief in my abilities has been an unwavering source of strength, even during the most challenging times. I am truly blessed to have you as my guiding light.

To my beloved son,

1) Wan Iman Mursi bin Wan Razishameer
2) Wan Iman Mustaqim bin Wan Razishameer
3) Wan Iman Muhaimin bin Wan Razishameer
4) Wan Rizq Muhammad bin Wan Razishameer

All of you have been my greatest inspiration and motivation. Your innocent smiles, warm hugs, and boundless curiosity have been the driving force that kept me going, even when the road seemed arduous. Thank you for your patience and understanding and for being my constant reminder of what truly matters in life. You are my most outstanding achievement.

I want to express my most profound appreciation and make a special dedication to my youngest son, Wan Rizq Muhammad. Your courage and resilience in battling epilepsy have been the driving force behind this research endeavour. Witnessing your struggles and the challenges you face on a daily basis ignited a fire within me to delve deeper into this realm, with the hope of contributing towards a better understanding and potential solutions. Your unwavering spirit and determination have been a constant source of inspiration, reminding me of the importance of this work and its potential impact on countless individuals like yourself.

To my beloved husband, Wan Razishameer bin Wan Razak, your patient understanding, emotional support, and ability to uplift my spirits have been instrumental in overcoming the obstacles that accompanied this endeavour. Your love, kindness, and reassurance have been my haven, providing me with the courage and determination to persevere. I am forever grateful for your presence in my life.

This accomplishment would not have been possible without the love, sacrifice, and support of my incredible family and supervisors. Your belief in me has been the driving force behind my perseverance, and for that, I am eternally grateful. I dedicate this work to my youngest son, Wan Rizq Muhammad, whose journey has inspired me to embark on this path with the hope of making a positive impact on the lives of those affected by epilepsy.

TABLE OF CONTENTS

LIST OF TABLES

Page

LIST OF FIGURES

Page

LIST OF SYMBOLS

χ^2	Chi-square
$<$	Less than
$>$	More than
$=$	Equal to
$\leq$	Less than and equal to
$\geq$	More than and equal to

LIST OF ABBREVIATIONS

AED	Anti-epileptic drug
ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control
CWE	Child with epilepsy
CI	Confidence Interval
CSI	Concealable Stigmatised Identity
CP	Cerebral Palsy
DEE	Development and Epileptic Encephalopathies
FNS	Family Needs Survey
JKM	Jabatan Kebajikan Masyarakat
KKM	Kementerian Kesihatan Malaysia
GLR	General linear regression
NGO	Non-governmental organization
NSW	Non-standard worker
OKU	Orang Kurang Upaya
PDK	Pemulihan Dalam Komuniti
R^2	Coefficient of determination
SD	Standard Deviation
SUDEP	Sudden Unexpected Death in Epilepsy
UNICEF	United Nations Children’s Fund
USM	Universiti Sains Malaysia
VIF	Variance Inflation Factor
WHO	World Health Organisation

LIST OF APPENDICES

KEPERLUAN YANG TIDAK DIPENUHI DALAM KALANGAN IBU BEKERJA KEPADA KANAK-KANAK EPILEPSI YANG MERUPAKAN PESAKIT HOSPITAL BERPAKAR DI KELANTAN

ABSTRAK

Latar Belakang: Ibu kanak-kanak epilepsi yang bekerja menghadapi pelbagai keperluan yang tidak dapat dipenuhi yang memberi kesan kepada kesihatan dan kehidupan mereka. Keperluan yang tidak dipenuhi ini berlaku apabila bantuan atau sokongan yang diperlukan untuk aktiviti harian tidak diperolehi. Sifat epilepsi yang tidak dapat diramalkan menyebabkan konflik kerja-keluarga yang teruk di kalangan wanita ini.

Objektif: Kajian ini bertujuan untuk mengenal pasti keperluan yang tidak dipenuhi dalam kalangan ibu kanak-kanak epilepsi yang bekerja, faktor-faktor penyumbang dan halangan yang menyumbang kepada keperluan yang tidak dipenuhi.

Kaedah: Ini adalah satu kajian kaedah campuran yang melibatkan gabungan kaedah kuantitatif (Fasa 1) dan kaedah kualitatif (Fasa 2) bermula daripada Februari sehingga Ogos 2023. Kajian Fasa 1 melibatkan 204 ibu kanak-kanak epilepsi yang bekerja dan berdaftar di Klinik Neurologi Pediatrik Kelantan, manakala Fasa 2 melibatkan 15 ibu bekerja yang terlibat di dalam Fasa 1 yang bersetuju untuk ditemubual. Borang Kajian Keperluan Keluarga telah digunakan untuk menganalisa keperluan yang tidak dipenuhi. Regresi linear am telah digunakan untuk menganalisis hubungan antara keperluan tidak terpenuhi dan faktor-faktor kajian. Analisis tematik telah digunakan untuk menganalisa halangan yang menyumbang kepada keperluan yang tidak dipenuhi dalam kalangan ibu bekerja ini.

Keputusan*:* Antara peratusan tinggi keperluan yang tidak dipenuhi adalah dalam domain perkhidmatan komuniti (81.6%), diikuti oleh domain maklumat (71.9%), domain sokongan sosial (53.1%), domain sokongan kewangan (43.2%), dan domain menjelaskan kepada orang lain (28.9%). Keperluan tidak dipenuhi yang paling rendah adalah domain fungsi keluarga (28.4%). Beberapa faktor penyumbang dikaitkan secara signifikan dengan keperluan yang tidak dipenuhi adalah menerima rawatan susulan di hospital sekunder, mempunyai anak yang mempunyai komorbiditi, bekerja di sektor kerajaan dan bekerja secara kontrak. Sebaliknya, faktor yang mengurangkan keperluan yang tidak dipenuhi adalah struktur keluarga nuklear dan mempunyai pekerjaan sepenuh masa. Hasil penemuan daripada kajian kuantitatif telah membimbing reka bentuk dan fokus bagi penerokaan kajian kualitatif seterusnya. Tiga tema utama yang berkaitan dengan halangan dikenal pasti dalam fasa kualitatif. Tema-tema tersebut adalah berkisar kanak-kanak epilepsi; "*Ketidakpastian dan kebimbangan yang berterusan untuk anak saya*", ibu bekerja; "*Saya dan kerjaya saya*", dan keadaan sekeliling; "*Saya tidak mendapat sokongan yang mencukupi*". Ibu melahirkan rasa tidak menentu dan bimbang tentang kesejahteraan anak mereka. Mereka juga bergelut untuk mengimbangi keperluan dan aspirasi kerjaya mereka sendiri. Selain itu, cabaran timbul daripada dinamik keluarga, dasar kerajaan dan jangkaan masyarakat.

Kesimpulan: Kajian ini menekankan keperluan yang tidak dipenuhi secara signifikan di kalangan ibu kanak-kanak epilepsi yang bekerja di Kelantan, menunjukkan kesan mendalam terhadap kehidupan harian dan kesejahteraan mereka. Keperluan yang tidak dipenuhi paling tinggi ditemui dalam perkhidmatan komuniti dan maklumat, menunjukkan jurang kritikal dalam sokongan dan sumber yang boleh diakses. Faktor-faktor seperti mendapatkan rawatan susulan di hospital sekunder, komorbiditi anak-anak, pekerjaan sektor kerajaan, dan kerja kontrak dikaitkan dengan keperluan yang tidak dipenuhi lebih tinggi, manakala struktur keluarga nuklear dan pekerjaan sepenuh masa mengurangkan keperluan ini. Penemuan kualitatif menunjukkan kebimbangan berterusan terhadap anak-anak mereka, kesukaran dalam mengimbangi keperluan peribadi dan kerjaya, serta kekurangan sokongan yang mencukupi daripada keluarga, kerajaan, dan masyarakat. Menangani keperluan yang tidak dipenuhi ini memerlukan pendekatan pelbagai aspek, termasuk peningkatan perkhidmatan komuniti, penyebaran maklumat, dan dasar sokongan untuk meringankan beban yang dihadapi oleh ibu-ibu ini.

Kata kunci: keperluan yang tidak dipenuhi, faktor penyumbang, halangan, ibu bekerja, kanak-kanak dengan epilepsi

THE UNMET NEEDS AMONG WORKING MOTHERS OF CHILDREN WITH EPILEPSY ATTENDING SPECIALIST HOSPITALS IN KELANTAN: A MIXED METHODS STUDY

ABSTRACT

Background: Working mothers of children with epilepsy (CWE) face a range of unmet needs and challenges that may impact their health and well-being. These unmet needs occur when assistance or support to perform everyday activities is not provided. The unpredictable nature of epilepsy causes severe work-family conflict among these women, potentially resulting in higher levels of unmet needs, which can further exacerbate the difficulties they encounter.

Objective: The objectives of this study were to identify the unmet needs among working mothers of CWE, its predictive factors, and the barriers leading to unmet needs.

Methodology: This was a mixed-method study involving a combination of quantitative (Phase 1) and qualitative methods (Phase 2) from February till August 2023. Phase 1 study involved 204 working mothers of CWE registered at the Paediatric Neurology Clinic in Kelantan, while Phase 2 involved 15 working mothers from Phase 1 who agreed to be interviewed. The validated Malay version of Family Needs Survey questionnaire was used to assess the unmet needs. General linear regression was applied to analyse the relationship between unmet needs scores and study factors. Thematic analysis was used to assess the barrier leading to unmet needs among the mothers.

Result: The quantitative study found the highest prevalence of unmet needs was observed in the community services domain (81.6%), followed by the 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%). Several factors were significantly related to higher unmet needs, including seeking follow-up care at secondary hospitals, having children with comorbidities, working in the government sector, and being employed on a contract basis. On the other hand, factors that reduced unmet needs included belonging to a nuclear family structure and having full-time employment. The findings from the quantitative component informed the design and focus of the subsequent qualitative exploration. The qualitative phase identified three main themes related to the barriers faced by working mothers of CWE. These themes centred on the child; "*Uncertainty and endless worrying for my child*", the mother; "*Me and my career*", and the surrounding circumstances; "*I don't receive enough support*". Mothers expressed constant uncertainty and worry about their child's well-being. They also struggled with balancing their own needs and career aspirations. Additionally, challenges arose from family dynamics, government policies, and societal expectations.

Conclusion: This study highlights the significant unmet needs among working mothers of CWE in Kelantan, emphasizing the profound impact on their daily lives and well-being. The highest unmet needs were found in community services and information, suggesting a critical gap in accessible support and resources. Factors such as seeking care at secondary hospitals, children's comorbidities, government sector employment, and contract-based work were associated with higher unmet needs, while nuclear family structure and full-time employment reduced these needs. Qualitative insights revealed persistent worry for their children, struggles in balancing personal needs and careers, and a lack of adequate support from family, government, and society. Addressing these unmet needs requires a multifaceted approach, including improved community services, information dissemination, and supportive policies to alleviate the burdens faced by these mothers.

Keywords: unmet needs, predictive factors, barriers, working mother, children with epilepsy

CHAPTER 1

INTRODUCTION

1.1 Background

1.1.1 Overview of Epilepsy

Epilepsy is described by two or more brief episodes of involuntary movement, frequently presenting with loss of consciousness, and sometimes has episodes of loss of bowel or bladder function (WHO, 2022a). However, there were various definitions of epilepsy. According to Beghi (2016), epilepsy is defined as recurrent unprovoked seizures with their causes and has biological, psychological and social complications. In addition, Sirven (2015) stated that epilepsy is a brain disease characterised by a predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of the condition. Epilepsy is not a disability, but it is a spectrum of disorders comprised of more than 25 syndromes with a range of severities, vastly varying seizure forms, and aetiology. The nature of epilepsy can be defined as unpredictable (Sirven, 2015). Unpredictable seizures in frequency, place, and time characterise them. Moreover, epilepsy has a bimodal onset that occurs more often in infancy and older adulthood (England *et al*., 2012).

The aetiology of epilepsy is diverse and multifactorial, encompassing genetic, structural, and metabolic factors. Genetic mutations and inherited epilepsy syndromes account for a significant proportion of cases, especially in children. Certain genetic disorders like tuberous sclerosis complex and neurofibromatosis type 1 also increase epilepsy risk (Ostendorf *et al.*, 2013; Griffith and Wong, 2018). Structural brain abnormalities disrupting normal development, such as cortical dysplasia, traumatic brain injuries, strokes, and brain tumours, can cause epilepsy (Adamczyk *et al.*, 2021).

Perinatal complications, including birth injuries, premature birth, and hypoxic-ischemic encephalopathy, may lead to epilepsy in children (Whitehead *et al.*, 2006). Inborn errors of metabolism, like phenylketonuria, if untreated, can result in epilepsy (Lin Lin Lee *et al.*, 2018). Infectious diseases involving the central nervous system, such as meningitis, encephalitis, and neurocysticercosis, are potential underlying causes (Singhi, 2011). However, in some cases, the aetiology remains unknown and is classified as idiopathic epilepsy (Shorvon, 2011). Epilepsy frequently involves a combination of genetic predisposition and environmental or acquired factors contributing to its development.

1.1.2 Prevalence of Epilepsy

Regarding prevalence, which represents the total number of cases existing in a population at a specific point in time, epilepsy is one of the most common neurological disorders worldwide, affecting around 50 million people (Ngugi *et al.*, 2010). The estimated global prevalence of active epilepsy (defined as individuals with ongoing seizures or requiring treatment) is around 6.38 per 1,000 people (WHO, 2022a). There was a significant difference in the prevalence between the countries. Epilepsy is estimated to affect 49 people out of every 100,000 in high-income countries each year, while in low- and middle-income countries, this figure can reach 139 per 100,000 people (Zack & Kobau, 2017). These variations in incidence and prevalence can be influenced by various factors, including age, sex, ethnicity, socioeconomic status, and access to healthcare services (Ngugi *et al.*, 2010). The most likely cause of the disparities is an increased risk of endemic diseases such as malaria or neurocysticercosis, a higher incidence of birth-related and motor vehicle accidents, variations in medical infrastructure, and a lack of access to preventive healthcare programmes (Minghui *et al.*, 2019). It is proven that almost 80% of people living with epilepsy in low and middle-income countries do not have access to treatment despite the availability of low-cost and effective antiseizure medications (Braslavsky & Sperling, 2022).

Children around the world are also affected by epilepsy. In underdeveloped countries, particularly in rural areas, the incidence is higher than in the general population (Peter & Carol, 2015). According to WHO (2022a), the prevalence of epilepsy in children ranges from 41 to 187 per 100,000 people. The incidence is reportedly highest in the first year of life and drops to adult levels by the end of the first decade. Approximately 1 in 150 children are diagnosed with epilepsy during the first ten years of life, with the highest incidence rate observed during infancy (Aaberg *et al.*, 2017). The first prevalence study in Malaysia discovered a lifetime epilepsy prevalence of 7.8 per 1000 population (Fong *et al.*, 2017). To our knowledge, there was no research done on the prevalence of epilepsy in children in Malaysia.

1.1.3 Comorbidities and Complications of Epilepsy

Epilepsy often co-occurs with various physical and psychiatric conditions that can profoundly impact the health and quality of life of affected individuals. According to WHO (2022), more than 50% of people living with epilepsy coexist with at least one other health condition. For instance, neuropsychiatric conditions frequently co-occur with epilepsy, including depression, anxiety, attention-deficit hyperactivity disorder and autism spectrum disorders (Beyenburg *et al.*, 2005; Berg *et al.*, 2017). They reported that prevalence rates for depression and anxiety in epilepsy range from 30-35%. These conditions are often under-recognized and can worsen seizure control and quality of life. The presence of psychiatric and physical comorbidities exacerbates seizures because the deleterious neurobiological processes interact with those producing seizures and are linked to increased treatment resistance (Fattorusso *et al.*, 2021). According to Kiriakopoulos (2019), psychiatric disorders were identified in

34.6% of children with seizures compared to 6.6% in the general population. Moreover, the risk of premature death among people with epilepsy increases about three times compared to the general population (Safurah *et al.*, 2013). It is due to accidents, drowning, status epilepticus, and sudden unexpected death in epilepsy (SUDEP). The incidence of SUDEP varies from one in 10,000 newly diagnosed epilepsy to nine in 1000 potential epilepsy surgery patients (England *et al.*, 2012).

Moreover, despite being on anti-epileptic medications, nearly 25% of children with epilepsy continue to have poor seizure control. Epilepsy is associated with developmental and functional impairments in children, such as poor academic achievement, behavioural and emotional dysfunction, and social incompetence (Karakis *et al.*, 2014). As a result, these children are more likely to have unsuccessful school experiences, difficulties in social engagement with peers, insufficient social skills, and low self-esteem. Even when antiepileptic medication has effectively controlled seizures, these issues may persist due to abnormal brain morphology or function, ongoing epileptic activity in the brain even when there are no symptoms, or adverse effects from antiepileptic medication (Kiriakopoulos, 2019a).

Additionally, there are common physical comorbidities, including migraine, stroke, cardiovascular disorders, and gastrointestinal problems (Elliott *et al.*, 2019). Migraine occurs in approximately 8-24% of epilepsy patients, and this comorbidity is associated with more refractory seizures (Amiri *et al.*, 2022). Stroke risk is increased two to three-fold in those with epilepsy compared to the general population (Perucca, Bahlo & Berkovic, 2020). Cardiovascular diseases like ischemic heart disease, heart failure and sudden cardiac death are also more prevalent, likely due to autonomic dysfunction and side effects of anti-epileptic medications (Elliott *et al.*, 2019). Gastrointestinal comorbidities such as dysphagia, gastroesophageal reflux and abdominal pain can result from recurrent seizures, anti-epileptic drugs or vagus nerve stimulation (Al-Beltagi & Saeed, 2022). Overall, comorbidities lead to poorer health outcomes, reduced quality of life, increased healthcare costs and higher mortality rates in epilepsy (Sirven, 2015).

1.1.4 Impact of Epilepsy on Caregivers

Beyond the direct effects on the child, epilepsy can also have a pervasive impact on family and caregivers' lives. Caring for a child or adult with poorly controlled epilepsy poses immense physical, emotional, and financial challenges for caregivers. Unpredictable and frequent seizures disrupt daily routines and require round-the-clock monitoring and care, which can be physically exhausting for caregivers (Yang *et al.*, 2020a). The need for constant vigilance also takes a toll emotionally, often leading to anxiety, depression, and social isolation (Koc *et al.*, 2019). Additionally, managing medications, doctor visits, testing, and other care needs for an individual with multiple comorbidities associated with epilepsy becomes overwhelming for caregivers (Rani & Thomas, 2019). Out-of-pocket costs for medications, special diets, equipment, and missed wages due to caregiving duties can add substantial financial strain (Piran *et al.*, 2017). Caregivers also frequently experience public stigma, discrimination, shame, and rejection due to the misunderstanding surrounding epilepsy, negatively impacting their mental health and quality of life (Sabo, Buttner & Scher, 2020a). Public stigma stems from myths that epilepsy is a form of insanity or mental retardation or that it is a result of a curse or supernatural forces (Mayor *et al.*, 2022). This leads to social rejection, distancing, and discriminatory behaviour towards patients and their caregivers.

The majority of studies found that parents of CWE had poorer quality of life (QOL) compared to general population norms and similar QOL among parents of children with other chronic conditions (Puka *et al*., 2018). Moreover, parents with CWE also experience more significant stress as they need to make decisions concerning the care and future of their children (Fong *et al.*, 2019). This is consistent with a study conducted in South China by Yang *et al*. (2020a), who showed severe anxiety, depression, and poor sleep quality among parents of CWE, especially in the infant group.

Compared to fathers, mothers are more affected. A study in Turkey to compare the effect of childhood epilepsy on parental QOL found that mothers are more affected and need more attention compared to fathers (Koc *et al*., 2019). Additionally, a study in Canada also found that mothers had poorer QOL compared to fathers (Puka *et al.*, 2019). Moreover, similar findings were also found in Malaysia. They found that mothers are usually at high risk for psychological distress, including depression and anxiety. Subsequently, the depressed mother will negatively impact their child's QOL, especially during the first two years after diagnosis (Wo *et al*., 2018a).

Several studies indicate that mothers and fathers of CWE face different realities, with mothers more profoundly affected and vulnerable to psychological distress compared to fathers (Wo *et al*., 2018; Koc *et al.*, 2019). Moreover, a few studies indicate that compared to fathers, mothers of CWEs tend to face greater caregiver demands, psychological distress, and work-family conflict (Ferro and Speechley, 2009; Karakis *et al.*, 2014; Koc *et al.*, 2019). Mothers spend more time providing hands-on care, such as administering medications, coordinating healthcare, supervising the child, and managing seizures (Luppi & Arpino, 2020). This intensive caregiving can negatively impact mothers' mental health, with higher rates of stress, anxiety, depression and social isolation compared to fathers (Jones & Reilly, 2016).

1.1.5 Impact of Epilepsy on Working Mothers

Despite epilepsy being a significant neurological condition worldwide, there remains a lack of research focused on epilepsy in the Malaysian context. Existing data examining the specific needs, challenges and burdens encountered by families and caregivers of CWE in Malaysia is limited, especially regarding the experiences of working mothers (Sitimin *et al.*, 2017). The unpredictable nature of seizures in epilepsy has led some working mothers to resign from employment to provide full-time care to their children (Wo *et al.*, 2018b). Research also demonstrates a negative impact on mothers' ability to work when caring for chronically ill or disabled children (Brekke & Nadim, 2017; Sitimin *et al.*, 2017). A study by Sitimin *et al.* (2017) reported that the work-family conflict is severe among working women with young children, especially infants with poor health conditions.

Considering the elevated caregiving responsibilities and increased risk of employment disruption faced by mothers, gaining an in-depth understanding of the unmet needs of working mothers of CWE in Malaysia is crucial. Such insight can guide targeted interventions to support mothers remaining in the workforce without sacrificing their children’s health and well-being. Focused research in this area also has the potential to advance more family-centred and gender-sensitive policies regarding epilepsy care in Malaysia.

1.1.6 Health care service provided to CWE in Kelantan and Malaysia

Malaysia has made progress in improving epilepsy care, but challenges persist, especially in ensuring equitable access to specialized services across the country (Raymond *et al.*, 2010). Major hospitals and tertiary care centres in urban areas, such as the Kuala Lumpur Hospital, Penang Hospital, and Sarawak General Hospital, offer comprehensive epilepsy care, including diagnosis, treatment, monitoring, and support services (Fong *et al.*, 2021).

In the state of Kelantan, located in the northeastern region of Peninsular Malaysia, the Hospital Raja Perempuan Zainab II (HRPZ II) serves as the main tertiary care centre for epilepsy (HRPZ II, 2023). HRPZ II, being a teaching hospital affiliated with the Hospital Universiti Sains Malaysia (HUSM), has a dedicated Neurology Department and an Epilepsy Clinic that provides specialized care for patients with epilepsy (Kamari, 2009). Services offered include comprehensive assessment, treatment planning, medication management, counselling, and follow-up care.

While HRPZ II serves as a hub for epilepsy care in Kelantan, other government hospitals and health clinics in the state may have limited specialized services for epilepsy patients. These facilities primarily provide general care and may refer complex cases to HRPZ II or other tertiary centres (HRPZ II, 2023). Patients residing in rural areas of Kelantan may face additional challenges in accessing specialized epilepsy care due to transportation difficulties and limited awareness about available services.

Organizations like the Malaysian Society of Neurosciences and the Chapter of Neurologists under the Academy of Medicine Malaysia have undertaken initiatives such as training programs for healthcare professionals, public awareness campaigns, and advocacy efforts to address these challenges (MyNIS, 2020). However, further efforts are needed to strengthen the epilepsy care infrastructure, increase the availability of specialized services in underserved areas, and address the socioeconomic and cultural barriers faced by patients and their families.

1.1.7 Government Initiatives Towards Epilepsy

The Malaysian government has implemented various measures aimed at supporting caregivers of people with epilepsy and reducing their burden. Public education and awareness campaigns led by the Epilepsy Council of Malaysia have worked to decrease the stigma against epilepsy patients and improve public understanding of the condition (Malaysian Society of Neurosciences, 2019). Healthcare for epilepsy is heavily subsidised at government facilities, reducing financial strain for families dealing with costly treatments and medications (Ku Abd Rahim *et al.*, 2020). Tax exemptions for medical expenses related to chronic illnesses offer additional financial assistance to caregivers (LHDN, 2022).

Malaysia also provides relatively comprehensive health insurance coverage and benefits like temporary paid caregiving leave to formally employed caregivers under the national social security system (Financial Development, 2020). Legislative actions have focused on upholding the rights of disabled individuals. The Persons with Disabilities Act was enacted by the Malaysian government in 2008 to protect and promote the rights of disabled people, including those with epilepsy with comorbid (Abdullah, Hanafi & Mohd Hamdi, 2017). This anti-discrimination legislation mandates equal opportunities for these people in critical areas such as employment, education, access to public facilities, transportation, housing, and healthcare. However, significant gaps persist in easing caregiver burden across communities in Malaysia, requiring concerted policy efforts and reforms.

1.2 Problem statement

Despite the status of epilepsy as a major global neurological health issue, there remains a significant lack of research focused on epilepsy in the Malaysian context, particularly regarding the experiences of families and caregivers of CWE. Extensive research has been conducted on parents and mothers of children with special needs, but there is minimal existing data specifically examining the needs, challenges, and burdens of working mothers of CWE in Malaysia. This is a cause of concern as several studies indicated that mothers of CWE tend to face greater caregiver demands, psychological distress, and work-family conflicts compared to fathers. The impact of epilepsy extends far beyond the medical realm, profoundly affecting family dynamics and maternal employment. In Malaysia, where traditional caregiving roles often fall to mothers, the burden of caring for a CWE can be particularly heavy. There is also a societal aspect to consider. The challenges faced by these mothers often remain invisible, leading to a lack of social support and understanding. This invisibility can result in isolation and further stress for the mothers and their families.

Furthermore, the rising number of working mothers in Malaysia reflects changing societal norms and economic necessities. The unpredictable nature of seizures requires constant vigilance, often forcing mothers to make difficult choices between their careers and their children's care needs. They face not only the stress of managing their child's condition but also the anxiety of potential seizures occurring while they are at work. This constant state of alertness can lead to burnout, depression, and other mental health issues, which are often under recognized and undertreated.

Poor understanding on the needs among working mothers may cause employers to be unaware of the unique challenges faced by these mothers, leading to inflexible work environments that fail to accommodate the unpredictable nature of caring for a CWE. The lack of adequate childcare facilities, and understanding of employers exacerbates the work-family conflict. The economic implications of this situation are substantial. When mothers reduce work hours or leave the workforce entirely to care for their CWE, it not only affects the family's financial stability but also impacts the broader economy through lost productivity and reduced workforce participation.

The healthcare system in Malaysia, while advanced in many respects, may not be fully equipped to provide the comprehensive, family-centered care needed for CWEs and their caregivers. Such limitation in the healthcare system puts additional pressure on mothers to become expert caregivers, often at the expense of their own well-being and career aspirations. The lack of research in this area in Malaysia means that policymakers and healthcare providers are working with incomplete information. Without a clear understanding of the specific needs and challenges faced by working mothers of CWE in the Malaysian context, it may be difficult to develop targeted interventions and support systems.

1.3 Rationale of the study

This study addresses this knowledge gap by providing an in-depth understanding of the specific unmet needs of Malaysian working mothers of CWE across different domains – including medical, psychosocial, educational, financial and employment. Identifying critical unmet needs and their associated factors may guide healthcare providers in delivering care that is tailored to meet the priorities of this group of mothers.

The findings also assist social services in introducing more flexible childcare and employment policies to support working caregivers of chronically ill children. While Malaysia has made progress in recent years, opportunities remain to enhance childcare support for working caregivers of chronically ill children. By identifying and understanding families' unmet needs, researchers can collaborate with policymakers to co-create innovative solutions that expand access to affordable, high-quality, and flexible childcare options tailored to these families' realities. For instance, our study findings could aid policies to provide subsidies and incentivise part-time and respite care services customised to manage children with chronic conditions.

Additionally, understanding the barriers that deter working mothers from attaining required supports and resources can enable policymakers to eliminate these obstacles, such as unaffordable care costs, inadequate workplace leaves policies, lack of community epilepsy resources, and stigma at the workplace through legal protections, awareness campaigns and policy reforms. Enhancing access to unmet needs has the potential to alleviate caregiver distress and improve overall family functioning and child wellbeing.

Examining the perspectives of working mothers is crucial, as mothers tend to take on greater caregiving responsibilities and experience higher psychological impacts than fathers. The study findings can highlight areas where targeted interventions are most needed to assist Malaysian mothers in balancing employment and care for a child with poorly controlled epilepsy. This can motivate healthcare and social service engagement and alert professionals to address policy and program gaps. Ultimately, meeting the unmet needs of these mothers is critical to supporting a better quality of life for CWE and their families in Malaysia.

1.4 Research Questions

a) What are the unmet needs among working mothers of CWE attending specialist hospitals in Kelantan?

b) What factors are associated with the unmet needs among working mothers of CWE attending specialist hospitals in Kelantan?

c) What are the barriers to the unmet needs among working mothers of CWE attending specialist hospitals in Kelantan?

1.5 Research Objectives

This part highlights the general and specific objectives of the research.

1.5.1 General Objective

To study the unmet needs, the associated factors, and the barriers among working mothers of CWE attending specialist hospitals in Kelantan.

1.5.2 Specific Objectives

a) To determine the unmet needs of working mothers with CWE specialist hospitals in Kelantan (Phase 1)

b) To determine the factors associated with the unmet needs of working mothers with CWE specialist hospitals in Kelantan (Phase 1)

c) To explore barriers to unmet needs among working mothers of CWE specialist hospitals in Kelantan (Phase 2)

1.5.3 Research Hypothesis

There is a significant association between mother characteristics, CWE characteristics, and employment characteristics with the unmet needs of working mothers of CWE attending specialist hospitals in Kelantan.

CHAPTER 2

LITERATURE REVIEW

2.1 Gender norms and expectations

Historically, societal norms have cast women primarily as caregivers and homemakers, responsible for the upbringing of children and the management of household affairs. This division of labor was clear and undisputed in many cultures for centuries, creating a deeply rooted expectation that persists even in modern times. Despite significant shifts in gender roles and increasing participation of women in the workforce, these traditional expectations continue to influence societal attitudes and behaviors (Vatres, 2019).

Therefore, this condition leads to working mothers often face a dual burden, balancing professional responsibilities with domestic duties (Sauer, 2022). They are typically expected to manage most household chores, including cooking, cleaning, and caregiving, regardless of their employment status. This expectation places immense pressure on working mothers, who must navigate time constraints and often sacrifice personal time and self-care to meet both sets of responsibilities (Dyson & Woodruff, 2017). The result is a significant imbalance, with working mothers frequently experiencing stress, fatigue, and burnout.

Additionally, gender norms also affect career progression for working mothers. There is a pervasive belief that mothers, especially those with young children, are less committed to their careers due to their family responsibilities. This bias can manifest in various ways, such as reduced opportunities for promotions, pay raises, and career advancement. Employers may hesitate to invest in the professional development of mothers, assuming they will be less available or reliable (Kinyua, 2022). Consequently, working mothers may find themselves trapped in lower-paying, less prestigious roles, despite having the skills and qualifications to advance.

Moreover, workplace policies often do not adequately support the needs of working mothers. Maternity leave policies vary widely, with some countries offering minimal leave and others providing more generous options. However, even where maternity leave is available, the transition back to work can be challenging without sufficient support. Flexible working hours, remote work options, and on-site childcare facilities are critical for helping working mothers manage their dual responsibilities. Unfortunately, such accommodations are not universally available, and many workplaces fail to provide the necessary support, leading to increased stress and difficulty balancing work and family life (Vatres, 2019; Sauer, 2022).

In addition, working mothers frequently face social judgment and guilt. Cultural norms that idealize the “stay-at-home mother” model contribute to feelings of inadequacy among working mothers, who may feel they are not devoting enough time to their children (Dyson & Woodruff, 2017; Kinyua, 2022). This judgment can come from various sources, including family members, peers, and even strangers. The pressure to conform to an idealized image of motherhood can exacerbate feelings of guilt and anxiety, making it even more challenging for working mothers to find a balance that works for them. The stress associated with balancing work and family responsibilities can have significant mental and physical health implications for working mothers (Ferro & Speechley, 2009; Luppi & Arpino, 2020). Chronic stress can lead to conditions such as anxiety, depression, and burnout. Physically, the demands of managing multiple roles can result in fatigue, sleep disturbances, and other health issues. It is crucial for working mothers to have access to mental health support and resources to manage these challenges effectively.

Despite the challenges, working mothers serve as important role models for their children, demonstrating resilience, hard work, and the ability to balance multiple responsibilities. They can inspire their children to pursue their own career goals and challenge traditional gender norms. By advocating for better support and understanding, working mothers can contribute to creating a more equitable and inclusive society for future generations.

2.2 Unmet needs among working mothers of CWE

Unmet needs refer to the gap between the services, resources, or support an individual requires and what is available or accessible to them. It represents a discrepancy between the identified needs and the ability to satisfy or address them effectively. According to Asadi, Packham and Gray (2003), unmet needs are "those needs that are identified but not satisfied by available services or resources". They further explain that unmet needs can arise for various reasons, such as lack of availability, accessibility, affordability, or acceptability of services or resources. Furthermore, Denham *et al.* (2020) define unmet needs as "the discrepancy between services judged necessary to manage a particular health condition and the perceived reality of the services received." This definition highlights the subjective nature of unmet needs based on the individual's perception of what they require and have access to.

A working mother can be described as a woman who manages to juggle her career alongside the additional duties of childrearing (Poduval & Murali, 2009). This general description can include two distinct types of working women: the stay-at-home mother who conducts her work from her residence and the woman who is employed outside of the home yet still meets her parenting responsibilities. Working mothers with caregiving responsibilities refer to women who are engaged and simultaneously tasked with providing care for a family member, such as a child, an elderly parent, or a relative with a disability or chronic illness (Menasce Horowitz, Parker & Graf, 2017). Research indicates that women often shoulder caregiving responsibilities, highlighting the challenges and importance of balancing work and caregiving duties (Menasce Horowitz, Parker & Graf, 2017).

Balancing a career with the caregiving duties required for a CWE is a significant challenge for working mothers. Their caregiving responsibilities span various aspects, including medication management. For working mothers of CWE, medication management is a crucial responsibility. Epilepsy is primarily treated with anti-seizure medications, and ensuring their child takes these medications on time and in the correct dosage is essential for controlling seizures and preventing potential complications (Eatock & Baker, 2007; Sirven & Shafer, 2014). These mothers must monitor their child's medication schedule, refill prescriptions on time, and be aware of potential side effects or adverse reactions. Failure to properly manage medications can lead to breakthrough seizures, which can be dangerous and disruptive to the child's daily activities and the mother's work routine (Foote, 2023).

Moreover, CWE typically requires regular follow-up appointments with neurologists or other healthcare providers to monitor their condition, adjust medication dosages if needed, and undergo any necessary tests or procedures (Karakis *et al.*, 2014). Working mothers often bear the responsibility of accompanying their children to these appointments, which can be time-consuming and may require them to take time off from work or make special arrangements (Bamber, Mahony & Spratling, 2023). They may need to coordinate their work schedules, arrange transportation, and ensure their child is prepared for tests or procedures. Additionally, they may need to communicate with healthcare providers, understand medical instructions, and advocate for their child's needs during these appointments.

Additionally, unpredictable seizures are a hallmark symptom of epilepsy, and working mothers of CWE must be prepared to respond appropriately when their child experiences a seizure episode. Seizures can occur unexpectedly, disrupting the mother's work routine and necessitating immediate attention and care (Kish, Haslam & Newcombe, 2020a). Lastly, epilepsy can have various impacts on a child's cognitive function, behaviour, and independence in daily activities. Working mothers of CWE often need to provide additional support and supervision to ensure their child's safety and well-being (Carter *et al.*, 2022). This may include assisting with personal care tasks, monitoring their child's activities, and ensuring they follow any necessary precautions or restrictions related to their condition.

The six most common unmet needs among mothers of CWE are obtaining information, social support, family functioning, community services, financial support, and explaining to others, detailed in the following sections. While a growing body of literature examines the unmet needs among parents of CWE, much of this research has taken a generalised approach without explicitly addressing the unique challenges working mothers face. Despite the increasing number of women in the workforce, there remains a dearth of studies explicitly investigating the unmet needs of working mothers navigating the complexities of balancing employment responsibilities with the caregiving demands of raising a child with epilepsy. The existing research has predominantly concentrated on the experiences of parents as a collective group, failing to account for the distinct obstacles and support requirements that may arise when a mother juggles her professional obligations alongside the care of a child with a chronic neurological condition. To the best of our knowledge, there has been a dearth of research examining the unmet needs among working mothers of children suffering from chronic illnesses, including epilepsy.

2.2.1 Unmet Need for Information

Unmet information needs refer to more access to accurate, comprehensive, and relevant knowledge and resources necessary for effectively understanding, managing, and coping with their child's condition while balancing their professional responsibilities (Thomas *et al.*, 2023).

A study conducted by Baca *et al.* (2011) addresses the informational needs of families of CWE by demonstrating the importance of recognising and managing psychiatric and neurodevelopmental comorbidities alongside epilepsy. The findings suggest that parents and caregivers should be informed about the potential long-term impacts of these comorbidities on their children's quality of life. It emphasises the need for holistic care approaches that include medical and mental health support, thus highlighting a significant area where families may require additional information and resources to support their child's overall well-being effectively.

A qualitative study conducted in Malaysia explored the needs and challenges among parents and CWE in childhood epilepsy care. They reported they needed epilepsy-related information. For example, parents need to find information from the internet, such as knowledge on care for an epileptic child and management during a seizure attack (Wo *et al.*, 2018b). The parents' insufficient knowledge about epilepsy led them to discourage their children from engaging in physical and social activities. It was because their parents believed that engaging in these activities would lead them to experience seizures, or if they did, nobody would know how to assist them. Moreover, Nevin *et al*. (2020) carried out a systematic review focusing on the information requirements of parents whose children have been diagnosed with early-onset epilepsy. The review revealed a strong desire for accessible, practical, and targeted information, emphasising the need for content addressing comorbidities and emotional support.

The unmet needs for information among parents of CWE occur because there is a significant information gap between parents and children diagnosed with epilepsy due to several factors. The CWE often struggle to articulate their questions, lack sufficient opportunities to inquire about their condition and have access to limited age-appropriate educational resources about epilepsy (Wo *et al.*, 2018b). Consequently, these young patients became disengaged and lost motivation to pursue information about their epilepsy. Therefore, it is important to inspire them to be active in gaining information for a better understanding of epilepsy, its causes and treatments, and self-care in the future. Additionally, caregivers who have an insufficient knowledge of epilepsy find it challenging to accept the diagnosis, lack the necessary coping mechanisms, and are more prone to experiencing significant stress. This correlation may account for the detrimental effects observed in the early stages following an epilepsy diagnosis. In contrast, caregivers of individuals who have been living with epilepsy for an extended period tend to face challenges related to the chronic nature of the condition (Bapat & Shankar, 2021).

A qualitative study conducted in the United Kingdom by Jackson *et al.* (2008) investigates the informational needs of parents caring for children with health conditions. Many parents took the initiative to conduct their research, mainly when they felt that the information provided by healthcare professionals was inadequate or while they were awaiting medical care (Wo *et al.*, 2018a; Jones *et al.*, 2019a; Nevin *et al.*, 2020a). This research emphasised that parents favour receiving information through one-on-one verbal communication, complemented by easy-to-understand written resources. They also appreciate being provided with a contact number for follow-up questions and place a high value on personalised information tailored to their child's needs. The study highlights the need for sensitive communication and adequate information provision to support the psychosocial well-being of parents and improve care for children with health needs.

In another study by Jones *et al.* (2019a), parents with young children having active epilepsy reported challenges in accessing knowledgeable professionals and desired integrated care and noted significant impacts on family functioning from epilepsy and associated neurobehavioral difficulties. The study emphasises the need for comprehensive epilepsy services that include neurobehavioral needs management and family-centred care, highlighting ongoing informational and emotional support needs beyond diagnosis.

Table 1: Summary of qualitative and quantitative articles on unmet needs of information

Author	**Countries**	**Findings**	**Recommendation**
(Baca *et al.*, 2011a)	United States	Parents and caregivers should not be informed about the potential long-term impacts of these comorbidities on their children's quality of life.	It emphasises the need for holistic care approaches, including medical and mental health support.
(Wo *et al.*, 2018)	Malaysia	CWE was concerned with the limitations epilepsy imposed on them, their relationships with peers, and their aspirations for independence and autonomy in the future.	It emphasises the importance of addressing both medical and psychosocial aspects of living with epilepsy.
(Nevin *et al.*, 2020)	Australia	Parents of children diagnosed with epilepsy at a young age expressed a strong desire for information that is easily comprehensible, practical, and specifically relevant to their situation.	It highlights a particular need for content about comorbidities and emotional support.

Table 1: Continued

Author	**Countries**	**Findings**	**Recommendation**
(Jones *et al.*, 2019)	United States	Parents with young CWE had difficulty accessing information from the professionals.	It emphasises the need for comprehensive epilepsy support.
(Bapat & Shankar, 2021)	India	The lack of infrastructure and cultural attitudes towards epilepsy compounds caregivers for individuals with epilepsy.	It emphasises the need for comprehensive resources on managing epilepsy, patient needs, and healthcare systems.

2.2.2 Unmet Need for Social Support

The unmet needs for social support among parents of CWE are multifaceted, reflecting the complex nature of caregiving in this context. Epilepsy's unpredictability and the diverse manifestations of seizures contribute to heightened stress and demands on parents, necessitating a broad spectrum of support services (England *et al.*, 2012). Social support needs can be categorised into emotional and instrumental support. Emotional support needs encompass the requirement for empathy, understanding, and psychological counselling to cope with the emotional burden of caregiving, while instrumental support refers to tangible assistance with caregiving tasks, financial aid, and healthcare services access (Yu *et al.*, 2022).

A study conducted by King-Stephens *et al.* (2020) reported that caring for CWE with a history of status epilepticus significantly disrupts daily activities. Work productivity and the ability to engage in activities were markedly reduced among adult patients and caregivers. Moreover, caregiving of children with chronic illness showed the highest levels of work absenteeism and the lowest employment rates (Kish, Newcombe & Haslam, 2018; Kish, Haslam & Newcombe, 2020b). Furthermore, many caregivers reported a considerable impact on their social lives, with nearly half stating that their social interactions were always affected (Mayor *et al.*, 2022).

A few studies found that parents of CWE reported a significant need for information and social support, particularly regarding treatment options, seizure management, and coping strategies (Wo *et al.*, 2018b; Yang *et al.*, 2020a; Olagunju *et al.*, 2021). They expressed a desire for access to support groups and resources specifically tailored to their unique experiences. Another study conducted by Nevin *et al.* (2022) reported that parents of children with developmental and epileptic