

Family Support and Challenges in Caring for Disabled Children in Malaysia: A Review of Literature

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Abstract

Purpose - This paper aims to review the literature related to family support and challenges in caring for disabled children in Malaysia.

Design/methodology/approach - A systematic search of studies published between 1994 to 2019 in American Academy of Pediatrics, Oxford University Press, Cambridge University Press, Routledge, SAGE Online, Springer Link, Taylor & Francis Online, Humanities and Social Sciences Collections, Wiley Online Library and Health Collections was undertaken to examine the support and challenges faced by families in caring for children with disabilities.

Findings - Studies have proven that family members faced a lack of psychological and structural support in caring for children with disabilities. This has led to an increase of challenges including social exclusion, stigma and discrimination, lack of academic structure and unmet healthcare needs for children with disabilities. Addressing shortcomings is vital to allow these children to prosper as an important member of society and fulfil their potential as human beings.

Originality/value - This paper is not currently under consideration, in press or published elsewhere. Effective collaboration between various agencies by providing more psychological and structural support for families and children with disabilities could enhance their social function and wellbeing. This can reduce negative implications on families and children with disabilities as well.

Keywords - Support, Challenges, Families, Disability, Children with disabilities

Paper type - Review Article

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I. Introduction

In Malaysia, the family is a fundamental part of social institutions and it plays a crucial part in children's growth and upbringing. This situation also applies to children with disabilities who are heavily reliant on their families, especially as they grow up. However, according to [1], most families with disabled children in Malaysia have the tendency of overprotecting their disabled children. This picture intensifies with families that are faced with poverty and demonstrate a lack of awareness of the children's capabilities and abilities. In most cases, these situations cause the children to be deprived from their basic needs such as health, recreation and employment.

As mentioned before, in some cases, family members considered children with disabilities as burdens. This creates tensions within the family dynamics which strain the relationship between siblings and the children. This creates a dysfunctional environment for children with disabilities to flourish and prosper as well [2].

II. Method

The literature for this review was derived from an extensive search of different databases, which include the American Academy of Pediatrics, Oxford University Press, Cambridge University Press, Routledge, SAGE Online, Springer Link, Taylor & Francis Online, Humanities and Social Sciences Collections, Wiley Online Library and Health Collections. This review included research papers published between 1994 to 2019. The search terms used in this paper included 'children with disabilities', challenges of children with disabilities, lack of support for families and children with disabilities. The search was narrowed down to find research papers written in the context of Malaysia and the Southeast Asian region. However, only several research papers on the Malaysian and Southeast Asian context were found. Thus, other research papers from other countries, including western countries were also included. A total of 56 articles including academic journals, books, research papers and reports were reviewed by the research team and the relevant data were extracted to support this review.

A total of 92 articles including books and report were obtained from the database search. Endnote version 7.1 reference manager software was used by the authors to import the details of these articles. A total of 37 articles that are deemed as irrelevant were removed by Endnote. The remaining 55 articles were then reviewed by all of the authors to extract the relevant data to support the purpose of this systematic review.

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III. Results

The literature search has resulted in different studies that focus on issues faced by families of disabled children. In this review, the discussion will be focused on studies regarding family support and challenges in caring for disabled children. This was narrowed down into the lack of psychological and structural support for families and children with disabilities. Another important point is the challenges that families and children with disabilities

faced such as social exclusion, stigma and discrimination and unmet healthcare needs. The results of the studies will then be discussed critically in the context of this review.

Disability in Malaysia

In Malaysia, due to its diverse multicultural population, there is a complex understanding of disabilities especially on the topic of stigma and religion [3,4]. The components of religion and spirituality are embedded into the understanding of disability in Malaysia. For example, a study in Sarawak involving children with down syndrome reported that Muslim families perceive that giving birth to disabled children is a predestined gift from God and God will assist them in taking good care of the child [5]. However, in some other cultural belief, there are the negative connotation surrounding children with disabilities. For example, having children with disability is the result of bad deeds throughout their life or during pregnancy [5] as shown by the Iban tribe in East Malaysia who believe that a child is disabled because of the mother had broken certain taboos [6].

Meanwhile, the Chinese community in Asia still holds the traditional belief of Karma, and viewed having children with disability as a manifestation of their ancestors' past moral misconduct [7]. Thus, this contributed to the stigma and discrimination that families with children with disabilities faced across the continent. They often relate a child's disability with something they did wrong in their previous life [3].

In terms of understanding the illness and behaviour, in many traditional Asia societies, a traditional healer are rooted in local belief systems and they believe in a traditional healer can treat the child disability [8,9]. Permanent chronic illnesses are often seen as a spiritual punishment for involving themselves in witchcraft and sorcery, or a result of demonic possession or ancestral heritance [9]. Despite this, in cases involving Malays and Chinese families in Malaysia, emotional, social and psychological causes of disability have been ranked higher than the physical and supernatural or religious causes [10].

The Lack of Support Family in Caring For Children with Disability

Previous findings show that family plays a significant role in the life of children with disabilities. However, families of children with disabilities receive low or incompetent support and assistance that impacted them emotionally and socioeconomically [11,12,13]. Due to the financial or geographical situation of the families, they had limited access in terms of care management for children with disabilities and the lack of services involving social care [14].

According to [14], due to these shortcomings, some children with disabilities have to grow up in institutional settings and were denied their rights to live with their families. This situation led to pressure and conflict as family caregivers have to sacrifice their time, energy, education and employment prospects to care for children with disabilities. Furthermore, this situation has created disruption in their family dynamics and caused disharmony and affect the social functioning of the families [15,16,17].

Psychological Support

In addition, [14] stated that psychological support for families with disabled children should also be targeted to their siblings and other family members or those who are directly or non-directly involved in caring for the children. The rationale of involving other family members is that they also might feel side-lined as extra attention is only to children with disabilities. This can be achieved through the provision of psychological and counselling services by the government sector or non-governmental organization. Aside from that, an open communication had to be practised to ensure every family member understand why the children with disabilities need the extra attention and to reduce conflict among able-bodied family members [15]. Primary caregivers have to be made aware of these situations in order for them to provide the necessary expectations and to maintain family dynamics.

Furthermore, the lack of skills and knowledge related to disability also causes families to struggle to cope in caring for children with disabilities [18]. The lack of skills and knowledge have resulted in caregivers feeling that the children are just a burden for them and hinder them from performing their everyday life activities [2]. Subsequently, this creates tensions within family members and causes harm to them psychologically.

Structural Support

In addition to the lack of psychological support, families of disabled children are facing a lack of physical or structural support. In most cases, having children with a disability requires both parents to be employed. However, due to the lack of disabled-friendly facilities or specialized day care centres, in most cases, one of the parents have to let go of their career to attend to the child's needs [14]. More infrastructures in the shape of disabled-friendly day-care centres and schools are needed to ensure the children with disabilities and their caregivers can lead a quality life as a family.

According to [14], most support and services are only available in the urban area. This causes those in the rural area not able to access the facilities and services provided by the government and non-governmental agencies. In some cases, even the information regarding related support services for families of disabled children are not reachable to the families in the rural areas.

Challenges for Families Caring of Children with Disabilities

In Malaysia, caring for own family members has been a tradition, especially among traditional families. This added social value is applied to ensure the well-being of the family members [19]. The same practice is applied to children with disabilities. However, living with their families comes with many challenges internally in their own family constitution and from the broader society.

Social Exclusion

In the Malaysian context, according to [1], the social exclusion of families of children with disabilities starts within the family constitution themselves. Due to fear, ignorance and devaluation, caregivers tend to overprotect children with disabilities from the outside world. This causes them to be deprived of their needs, such as the need to play, interact and to be involved in recreational activities.

Growing up within these types of environments causes children with disabilities and their families to have a low quality of life. This deprives their opportunities for children with disabilities to grow into an independent and self-sufficient human being. Subsequently, children with disabilities are denied of the opportunity to create a close and dependent relationship with their family members [20]. They will not be able to experience an effective caring system that emphasizes love, care and unity.

Stigma and Discrimination

Children with disabilities and their families are also facing stigma and discrimination resulting in negative attitudes from society. These behaviours or attitudes create barriers, refusing the rights and dignity and challenge social integrity and equality of the families of children with disabilities [21]. The stigmatisation process of disabled children and their families will cause further systemic isolation from their social, cultural and political opportunities. Furthermore, this further restricts the participation of disabled children and families in the community and will cause their invisibility and vulnerability to be exploited to increase [21].

Stigmatisation can be described as when a person's identity or their social group, face negative connotations by the broader society [22,23,24]. In Asia, perspective and diverse socio-cultural context need to ease a proper understanding of how stigma works to affects individual people and their families in a particular location [25,26]. By linking themselves with the social stereotype, children with disabilities confidence and self-assurance will be damaged and resulting in social isolation and reluctance to engage with the public [9].

Evidence suggested that for the disabled person and their families to improve their life's quality, they must actively raise their concerns and be involved in the decision-making process [27]. In contrast, the stigmatisation and discrimination in the society today does not internalize the inclusion of children with disabilities in the process of decision making regardless of their capabilities and abilities. The tendency to lower the expectation about the capability of children with disabilities capacity strengthen beliefs that every disabled person are not able. This will further give to low confidence and lack aspirations, contributing the children with disabilities and their families to self-stigma [28,29,30].

Furthermore, stigmatisation towards children with disability will heavily affect those affiliated with them as well. On top of that, further investigations into dissimilar forms of stigma across Asia have found that family plays a fundamental part in the stigmatisation and discrimination [9]. Plenty of evidence suggests which highlighted that raising a disabled child significantly affects families' quality of life [9,31,32]. Members of the family can also be targeted to stigma and negative attitudes. This occurs to mothers of the disabled, who are held accountable and blamed for giving birth to a disabled child [6]. As an example, a study in Sarawak that assesses the quality of life of mothers with down syndrome children identifies that associations that are supposed to support children with down syndrome were divided according to particular background characteristics such as rural locality, race, and ethnicity [33]. This type of division creates a more divisive community as the background is more important than the best interest of the child.

Stigma and discriminatory attitudes also correlated with disability type. In Kuala Lumpur, mothers with autistic children and mothers with intellectually disabled children held negative connotations about and towards disability, whilst mothers of children with down syndrome perceived disability more positive light [33]. A negative parental attitude could limit children with disabilities opportunities to be a functional and contributing member of society. Thus this can create barriers to vocational training and formal employment for children with disabilities [34].

Academic Structure

In general in Malaysia, it was suggested that teachers teaching children with disabilities are not well informed or lack the competency to educate children with disabilities [35]. Children with disabilities are said the need to gain academically from spending time in a designated class only for disabled children. Despite the committed efforts of the Malaysian government to include children with disabilities in a mainstream school, views appear to have become more visible that teachers in Malaysian do not have the proper training and skillset to support disabled children to study together with other children in the same classroom [35].

In addition to that, the negative perception of disabled children and their families have emerged from the teachers. Teachers particularly have proved they are facing difficulties in doing their respective tasks since they are the first person to teach disabled children. This situation causes families to express their lack of confidence in the teachers in teaching children with disabilities [36]. [37] proposed that Malaysia is not yet ready for inclusive education because of the lack of facilities and infrastructure, including physical and support structures and teaching personnel. Malaysian teachers are viewed as not prepared for inclusion, and there is a need to address teachers' attitudes towards inclusion. Building teachers' confidence level and skillset will change the negative perception towards disabled children and their families should be prioritized by decision-makers for the further professional development of the academic activities related to children with disabilities [38,39,40].

Healthcare Needs

According to [41], in most middle-income countries like Malaysia, the estimated percentage of children with disabilities with unmet needs is approximately 50% to 75% for recovery and rehabilitation services, and 60% to 80% have unfulfilled needs for assistive devices. Furthermore, 50% have unfulfilled needs for the services of a dentist, speech therapist, and home care nurse. Only 23.5% of children with disabilities do not have any needs unmet. This figure shows that there is a significant unmet need regarding the healthcare of children with disabilities. The primary reason for the lack of healthcare needs is the unavailability and inaccessibility of services. This includes inaccessibility in terms of the monetary which the services are too expensive. At the same time, families could not find the right time to access the services and geographically where it is not available near the families of children with disability location [41].

Furthermore [42], logistical challenges such as the lack of skilled medical staff, and limited resources limit families of disabled children to obtain health services. UNICEF also reported that there is a lack of skilled healthcare providers such as physiotherapists, occupational therapists, clinical psychologists and psychiatrists who

are well-trained to work with children with disabilities across multiple health centres in Malaysia. This situation causes health care providers to limit their human resources only to restricted screening, intervention and rehabilitation which would later affect the state of care services received by the children with disabilities. Healthcare centres are concentrated in urban areas and weak infrastructure continues to hamper the delivery of healthcare and rehabilitation to communities in rural areas and the urban poor.

Moreover, children with disabilities have been suffering from poor mouth health and nutrition with further emphasize on services such as dental and dietary [43,44]. In addition, according to [45], in Malaysia, dental care is the most commonly unfulfilled health needs among disabled children. Oral health and nutrition in the health care of disabled children are not integrated by medical professionals as they view that these issues are not important when the children have other medical complication.

Children with disabilities in Malaysia face difficulties to access speech therapy services and the use of communication aids. These unmet needs are more prevalent compared to the needs of vision, hearing aids and mobility [46,47,41]. Studies have shown that this is because of the technical challenges to authorize communication aids prescription. In this light, there is a low priority given to communication compared to different disability [48]. On top of that, the unmet needs of children with learning disabilities, intellectual impairment and behavioural problems are more common than those who have other disabilities [49,41,50]. According to [49], intellectually disabled children are more likely to be denied therapy compared to other children with other disabilities. [50] also stated that children with autism are not in the receiving end of healthcare services compare with other children with other functional disabilities. The dominant reason behind issues faced by children with intellectual and learning disabilities is believed to be because of their disabilities not being visible or able to see with the naked eye. In addition, to conversing and interacting with children with learning and intellectual disabilities are considered to be more challenging than other children [41].

However, there are also cases where healthcare providers communicate poorly and underestimate people with disabilities and their family abilities [51]. At the community level, it is expected that community-based rehabilitation (CBR) workers function can perform their tasks adequately at mid-level by providing disability-focused rehabilitation and education services under guidance from relevant professionals. However, this has not been the case as CBR workers receive limited training, limiting the level of tasks they can perform. Due to these limitations, CBR centres, at their best, are only able to address mild to moderate disabilities [52]. This is seen as a great shortcoming, as the children with disabilities are routinely referred to their nearest CBR centres and those with severe disabilities are not being able to have their needs met [42].

According to [41], in terms of the prevalence of unmet needs for disabled children in Malaysia, it is considered higher than in the most developed nation, but it is still low if we are comparing with middle and low-income countries. However, this comparability is restricted at the international level due to the usage of multiple definitions, diverse population and different measuring tools in capturing unfulfilled needs for disabled children.

The efforts done by the Philippines Ministry of Health to put more therapists at health centres has been an excellent step to move forward to make services closer to the community. The idea behind these efforts is to meet the rehabilitation needs of persons with disabilities in rural areas where there are restricted professional services available [53]. Currently, in Malaysia, most specialized therapy and rehabilitation services are still based in major town's hospitals which are not entirely accessible to everyone. Thus, Malaysia can follow this effort as we faced similar challenges. Although the effort to improve services in the community has improved in Malaysia, clearly, more initiatives and programme need to be done to further increase the effectivity and volume of services provided.

IV. Conclusion

In conclusion, in combatting stigma and discrimination, an increase in interaction between people with disabilities and other community has resulted in more positive attitudes and behaviours towards disability [54,55]. This can prevent stigma and discrimination from leading disabled persons to be isolated and withdrawn from participating in public. Furthermore, policymakers and non-governmental agencies can play a bigger role by increasing outreach programmes for families of children with disabilities who are not able to access and afford the currently available services and support. Greater emphasize has to be given to those who live in the rural community and for those in the low-income families to ensure that they are not left behind in receiving ample needs and services that are already available in Malaysia. Thus, in creating a system where individuals from all sort of background able to access support and services, Malaysia can move a step towards improving the social functioning of disabled children and their families. In line with Malaysia's Person with Disabilities Act (2008), more effective and active collaboration between agencies such as the Department of Social Welfare of Malaysia and the Ministry of Health of Malaysia can help reduce the increasing unmet needs faced by disabled children in Malaysia.

In a nutshell, Malaysia needs to enhance social care support and assistance for children with disabilities and their family member as well. As part of country members that rectify the Conventions of the Right of Persons with Disabilities, Malaysia has to prioritize the prosperity of children with disabilities as their main priority in making sure support especially in terms of psychological and structural are met. On top of that, families of disabled children also need assistance in terms of accessibility of services and information as well as financial assistance for those who are in the low-income community. By doing this, Malaysia can protect children with disabilities from exploitation and psychosocial challenges. This can reduce negative implications on children with disabilities in living their life to the full of their potential and capabilities in order for them to contribute back to society.

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