THE LIVED EXPERIENCES OF CAREGIVERS CARING FOR PERSONS WITH INTELLECTUAL DISABILITIES (PWD)

MOHD IQBAL HAQIM BIN MOHD NOR

UNIVERSITI SAINS MALAYSIA

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by

MOHD IQBAL HAQIM BIN MOHD NOR

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LIST OF ABBREVIATIONS

BJIM	Division of Industry and Community Network
CBR	Community Based Rehabilitation
CRC	Convention on the Rights of a Child
CRPD	Conventions on the Rights of Persons with Disabilities
CST	Caregiver Skills Training
DSW	Department of Social Welfare
ID	Intellectual Disabilities
MOE	Ministry of Education
MOH	Ministry of Health
MWFCD	Ministry of Women, Family and Community Development
NGO	Non-governmental Organisations
PWD	Persons with Disabilities
PWLD	Persons with Learning Disabilities
PWMD	Persons with Mental Disabilities
ToT	Training of Trainers
UNICEF	United Nations International Children‟s Emergency Fund
USM	Universiti Sains Malaysia
UN	United Nations
WHO	World Health Organisations

LIST OF APPENDICES

PENGALAMAN HIDUP PENJAGA YANG MENJAGA ORANG KURANG UPAYA INTELEKTUAL (PWD)

ABSTRAK

Kajian ini bertujuan untuk mengkaji pengalaman hidup penjaga yang menjalankan penjagaan kepada orang kurang upaya intelektual (PWD) di Malaysia. Aspek yang dikaji memfokuskan kepada impak menjalankan penjagaan kepada penjaga serta strategi daya tindak penjaga dalam menjalankan penjagaan terhadap PWD. Kajian ini turut mengenal pasti sistem sokongan sosial penjaga serta keperluan penjaga dalam menjalankan penjagaan terhadap PWD. Kajian kualitatif ini menjalankan temu bual mendalam kepada 18 orang penjaga yang menghantar anak PWD mereka di Pertubuhan Pemulihan Dalam Komuniti (PPDK), USM. Data yang dikumpul telah dianalisis dengan menggunakan aplikasi ATLAS.ti 9. Dapatan kajian mendapati antara impak terhadap penjaga termasuk konflik keluarga, kesihatan fizikal, mental dan emosional, pekerjaan penjaga, implikasi ekonomi, stigma dan diskriminasi serta impak sepanjang pandemik COVID-19. Seterusnya, dapatan kajian mengenal pasti strategi daya tindak penjaga anak kurang upaya. Strategi daya tindak ini terbahagi kepada dua, strategi daya tindak mengatasi isu dan cabaran sebagai penjaga dan strategi daya tindak mengatasi stres dan tekanan sebagai penjaga. Kajian ini turut mengenal pasti sistem sokongan penjaga berfokus kepada sistem sokongan social formal dan tidak formal. Selain itu, dapatan kajian turut mengenal pasti keperluan penjaga seperti kumpulan sokongan, bantuan kewangan dan ekonomi, tambahan dan penambahbaikan latihan yang relevan terhadap penjaga, pengubahan pendekatan oleh penggubal polisi, penambahbaikan perkongsian maklumat, penambahbaikan

perkhidmatan yang disediakan terutamanya jam operasi perkhidmatan, pengurangan stigma dan diskriminasi serta penambahan sokongan sepanjang tempoh pandemik COVID-19. Selain itu, berdasarkan dapatan kajian, pengkaji mencadangkan dan membentuk model intervensi kerja sosial bagi penjaga dalam menjalankan penjagaan kepada PWD. Akhir sekali, implikasi dan limitasi dalam kajian ini telah dibincangkan bagi membentuk hala tuju kajian masa hadapan bagi bidang ini**.**

THE LIVED EXPERIENCES OF CAREGIVERS CARING FOR PERSONS WITH INTELLECTUAL DISABILITIES (PWD)

ABSTRACT

This study aims to explore the lived experiences of caregivers caring for persons with intellectual disabilities (PWD) in Malaysia. The objectives of this study focus on impact of caregiving on caregivers and caregivers' coping strategies in caring for PWD. This study aims to identify the support systems and the needs of caregivers in caring for PWD. This qualitative study conducted in-depth interviews with 18 caregivers of PWD children that acquire services from Community Based Rehabilitation (CBR) USM. Process of data collection and analysis was assisted using the ATLAS.ti 9 application. Findings revealed that impacts on caregivers include family conflicts, physical, mental and emotional health, caregiver's employment, economic implications, stigma and discrimination, and impact of the COVID-19 pandemic. Findings also identified caregivers' coping strategies which are divided into two coping strategies to overcome issues and challenges and coping strategies to overcome stress and pressure. Study identified support systems for caregivers focus on formal and informal social support systems. Study identified caregivers' needs such as support groups, financial and economic assistance, relevant training and improvement, policy changes, improved information sharing, improved services, particularly service hours, reducing stigma and discrimination, and additional support during COVID-19 pandemic. The researcher recommends a social work intervention model for caregivers in caring for PWD. Finally, the implications and limitations of this study are discussed including the direction of future research of similar studies.

CHAPTER 1

INTRODUCTION

1.1 Introduction

This study discussed the lived experiences of caregivers for persons with intellectual disabilities. This study explores the aspects of their lives that involved issues in their roles as caregivers, their specific needs as caregivers, and how they coped with the challenges. This chapter elaborates on the background of this study, research problems, research questions, objectives, and significance of this research.

1.2 Background of Study

Understanding disability in Malaysia's multicultural population has become a complex predicament due to the topic of stigma and religion perspectives on disability (Sheri, 2015; Ling, 2007). As a country with rich cultural background, a study in Sarawak, a state in Malaysia on down-syndrome children, reported that the Malay Muslim communities viewed having down-syndrome children as a present from God and God will pave the way for them to raise the child (Chan, 2012). However, different cultural and religious beliefs that contradict this connotation as negative images surround children with disabilities. Another study on Iban communities in East Malaysia belief a child is disabled because the mother has broken certain taboos that their cultural or religious belief forbids (Mamba, 2010). These elements of religion and spirituality are fundamental in understanding concepts of disability in Malaysia.

Matters involving medical and caregiving services for people with disabilities in Malaysia adopts this concept as well. Many traditional Asia societies still rely on traditional healers to treat children with a disability instead of modern medical approaches (Botros et al., 2006; Lauber & Rössler, 2007). Despite this, studies

involving Malays and Chinese communities in Malaysia concluded that the role of emotional, social and psychological causes of disability is greater than the supernatural or superstitious causes of disability (Edman & Koon, 2000).

The World Health Organization (WHO) defines intellectual disability as a significantly reduced ability to comprehend complex information as well as learn and apply new skills in daily life. This reduced ability results in decreased social functioning, which begins to affect them before adulthood and has a lasting effect on personal development (World Health Organization, 2020).

In general, according to the American Psychiatric Association (2017), persons with intellectual disabilities faced issues related to their intellectual and adaptive functioning. Intellectual functioning impaired their learning and problem-solving ability, while adaptive functioning impacted their daily living skills such as communicating and performing basic independent living skills.

Statistics showed that intellectual disability affected one percent of the total population and was more likely to be diagnosed in males than females. Furthermore, statistics also support that 85 percent of those affected suffered from mild intellectual disability or borderline intellectual disability (American Psychiatric Association, 2017).

1.2.1 Caregivers Caring for Persons with Intellectual Disabilities (PWD)

PWD faced numerous issues and challenges in obtaining family support in their recovery and caring process (Fatimah et al., 2013). Issues within a PWD family institution are no longer uncommon in Malaysia. This contradicts with the social norms in Malaysia, where family institutions are often reported to remain solid and supportive in facing struggles and challenges (Joseph, 2000; Deva, 2004).

This situation is mainly because many Malaysian believe that PWD are caused by an evil spirit or any other superstitious means (Mohamad et al., 2011). This creates taboo and stigma attached to the PWD, in certain cases up to the extent of their family abandoning them.

Furthermore, studies involving PWD in Malaysia are still lacking. Existing research is only conducted for specific ethnicities and races, preventing a holistic representation of PWD in Malaysia, which failed to reflect the multicultural diversities of the nation (Mohamad et al., 2011). In addition, inadequate support from families in Malaysia in creating a conducive living environment for PWD has seen PWD's living situation to be unhygienic and disorganized (Fatimah et al., 2013). This shows that the family needs to play a pivotal role in the care and recovery process of PWD. This can help PWD live a prosperous and productive life.

In the west, family institutions of PWD are fragile because families blame issues within their family members are often caused by the disability of PWD (Robinson, Rodgers & Butterworth, 2008). This creates tensions within the family institution and affects family members' relationships. Furthermore, western literature also showed that the presence of PWD, is often thought to be a burden to families because most western families assume that PWD are unable to contribute anything to them (Shakespeare, 2008).

Families of PWD often fail to recognize the importance of how the integration of PWD and their families are fundamental to the recovery of PWD. Separation from familial support can cause detrimental effects on the PWDs, particularly in their caring and recovery processes (Aizan et al., 2016).

Family and caregivers are the fundamental support system of an individual. If they fail to receive the support they need, they cannot function well like any other

individuals. Thus, families need to learn how to provide support and appraisal to other family members (Kaur & Arora, 2010). Failure to do so causes high tension within the family institution and cause friction within family environments. The same can be said for PWD.

Despite proven issues and challenges PWD and their family faced, literature also proved that PWD could improve their decision-making in life with the right support and dedication from families and caregivers (Low & Lee, 2015). This demonstrates that it is not impossible to create a happy and dynamic family institution for PWD and their families.

The statement highlights the importance of empowerment process for PWD and their families in Malaysia. Furthermore, in Malaysia, PWD's families are not receiving enough support from responsible bodies regarding their predicament (Fatimah et al., 2013). The lack of support could be the cause of why families and caregivers often choose not to take responsibility for PWD.

1.3 Problem Statement

Generally, a person with intellectual disabilities (PWD) suffers from problem involving their intellectual and adaptive functioning. Thus, this disability impaired their learning and problem-solving ability and affected their daily living skill, such as communicating and performing basic independent living skills (Ministry of Health Malaysia, 2011; American Psychiatric Association, 2017; Jabatan Kebajikan Masyarakat, 2020; World Health Organization, 2020). This inability impacts those around them, particularly their family members and caregivers.

Since 2009, there have been seven categories of PWDs in Malaysia. Two out of the seven categories consist of intellectual disabilities; they are persons with learning disabilities (PWLD) and persons with mental disabilities (PWMD). The latest

available statistics suggest that as of 2018, PWLD and PWMD comprise 34.2 percent and 8.3 percent, respectively from the total PWDs in Malaysia (Jabatan Kebajikan Masyarakat, 2018). This proves that PWD consist of 42.5 percent of the total of PWDs in Malaysia, which is the highest percentage for PWDs across all seven categories of PWDs in Malaysia.

In western countries, caregivers and families often blame the disability of PWD for their family hardships (Robinson, Rodgers, & Butterworth, 2008). The existence of PWD in their family is often thought to be burdening as most caregivers and families assume that PWD are unable to contribute back towards them (Shakespeare, 2008). Most families and caregivers in Malaysia, regardless of ethnicity, believe that the reason behind the disability of PWD comes from superstitious and evil means and thus create a culture that jeopardizes the relationship between caregivers and PWD (Mohamad et. al., 2011). Families and caregivers also failed to comprehend the importance of PWD caring for family and receiving support from caregivers and family. Most of them are not aware that the fastest road to recovery and regaining PWD life purpose is through integration with families. This is supported by Aizan (2016), stating that the removal of a person with disabilities (PWDs) from their family environment has the potential to impact PWDs negatively.

In most instances, caregivers and PWD have an immense impact on each other due to the dependency on PWD and caregivers being the only pillar of support for PWD (Iqbal, 2018). Studies have shown caring for PWD impacted caregivers negatively due to the required extra attention and commitment from their caregivers and family (Robinson et al., 2008; Kaur & Arora, 2010; Mohamad et al., 2011; Mohamad et al., 2012, Firdous et al., 2019; John, & Zapata, 2017; Kalgotra, & Warwal, 2016; Patton et al., 2018; Shahrier et al., 2016). The negative impacts are the

negative family relationship between PWD and their families; stress among caregivers caring for PWD; stigma and discrimination; economic implications, effects on caregivers' employment and impacts during the recent COVID-19 pandemic.

The first negative impact revolving PWD is the negative family relationship between PWD and their families (Fatimah et al., 2013; Mohamad et al., 2011; Robinson, Rodgers & Butterworth, 2008). This issue is related to the family institution, such as the absence of family and caregivers that are supposed to be individuals' main social support system. PWD in their families faces a lack of support as most parents and caregivers do not know how to provide emotional and psychological support to their PWD child (Kaur & Arora, 2010). Their failure to do so results in the worsening conditions of PWD's lifestyle and causes great pressure and tension towards caregivers (Robinson et al., 2008). This creates a toxic and inconducive family environment for the PWD (Kaur & Arora, 2010). This situation contradicts the social norm in Malaysia, where family institutions are often characterized with solidarity and supportiveness (Joseph, 2000; Deva, 2004).

Secondly, according to Bowlby (1969), children's early life experiences are vital in shaping children's behavior and development. The same situation applies to PWD. However, research shows that caregivers with children with a disability faces a more significant amount of stress compared to those who do not have children with disabilities (Boyd, 2002). This result in stress among caregivers caring for PWD. For example, most mothers spend most of their time caring for the PWD due to the inability of some of them to accomplish their daily basic living skills. Although it depends on their level of disability, this shows excellent dependency as caregivers must assist them sometimes to eat or how use the bathroom (Catherall & Iphofen, 2006; Glidden &

Schoolcraft, 2007). The time consumed and dependency towards caregivers advocate the build-up stress the caregivers caring for PWD face.

On top of that, there is still a lack of exposure and misleading information on mental health and PWD globally (World Health Organisation & World Bank, 2011). This lack of exposure and research creates misconceptions and misleading information on the lived experiences of PWD and their families to the extent that they are discriminated against and stigmatized (Hanafiah & Bortel, 2015; Kirmayer & Pedersen, 2014; Knox et al., 2013; Robles-García et al., 2013). According to a study by UNICEF Malaysia (2017), PWD are facing the highest percentage of stigma if compared to any other category and 58 percent of the public claims that they do not want to live near or in the same neighbourhood as children with intellectual disabilities (UNICEF Malaysia, 2017). These factors are facts and figures to support that stigma and discrimination exist towards PWD in Malaysia (Hanafiah & Van Bortel, 2015; Knox et al., 2013; Chong et al., 2013).

In addition, according to Fatimah et al. (2013), caregivers caring for PWD are more likely to face an economic burden. In Malaysia, most caregivers and families caring for PWD live in poverty. The issue is highlighted when PWD is denied rights as other PWDs such as monthly allowance and benefits of license renewal that a PWDs is entitled to (Hasbeemasputera, 2014). The same situation occurs in the West, where study has shown there is an issue of lack of viable employment available for PWD (Lockwood, 2014). This negates PWD efforts in becoming economically independent from their caregivers and family and thus inflicts extra economics burden on their caregivers.

Besides, the issues of economic burden also relate to the social support received by caregivers caring for PWD. The lack of formal and informal social support

for PWD and their caregivers can be seen in their disorganised and unhygienic housing environments (Fatimah et al. 2013). The lack of support from responsible bodies contributed to why most caregivers chose to institutionalize PWD (Iqbal, 2018). This is speculated to occur due to the distraught faced by the caregivers on how to manage the PWD. The lack of formal and informal social support for family and caregivers caring for PWD can disintegrate rapport between caregivers and PWD (Iqbal, 2018). Ample support sees PWD and their caregivers able to contribute fully to society and live productively.

Furthermore, having appropriate coping strategies is fundamental in improving the social functioning and livelihood of caregivers caring for PWD as they face a significant amount of tension and pressure impacted by caring for the PWD (Firdous et al., 2019; John & Zapata, 2017; Kalgotra, & Warwal, 2016; Patton et al., 2018; Shahrier et al., 2016). However, the effectiveness of the coping strategies depends on the social services and support they receive as both are interrelated (Dusselier et al., 2005; Nahid & Sarkis, 1994). Thus, caregivers caring for PWD need to receive formal and informal social support to assist them in overcoming the negative impact that they are facing (Bowen, 1966). Successful coping strategies have also been proven to improve caregivers' and PWD prospect of life (Wood et al., 2007; Moskowitz, 2011). This shows the need for coping strategies of caregivers caring for PWD to be further studied and explored to identify the successful coping strategies that have been used in Malaysia.

Past studies have indicated that, the fundamental needs of caregivers caring for PWD is the skills and knowledge in coping with caregiving for PWD. The inability to demonstrate skills and knowledge can jeopardize the development of PWD life and negatively affect their life (Sarvananthan, 2019). As an example, children with

intellectual disabilities tend to be more sensitive and are more prone to tantrums (Wingert et al., 2008). In most cases, this occurrence happens due to the caregiver's lack of non-verbal communication skills, which causes difficulty in PWD to project their wishes and intentions. This shows that caregiving for PWDs is incredibly challenging and requires total commitment to absorb the skills and knowledge needed to succeed (Yekutiel et al., 1994). According to Cuzzocrea et al., (2013), there is also a need for effective training and skills for parental caregivers as they are more emotionally and physically invested in caring for PWD. The recent lockdown and restricted movement control order due to the COVID-19 has pushed caregivers to be resourceful and creative in obtaining medical consultation and educational services that they need (Eshraghi et al., 2020). Mainly they identified that the challenges that they faced was to find access towards therapeutic services and intervention according to fulfill PWD needs (Liptak et al., 2006; Boulet et al., 2009).

Currently, even though existing studies on PWD are increasing, the research gap is evident as most studies focus on medical perspectives towards disability which involve treatment and care on PWD themselves and do not involve caregivers (Robles-García et al., 2013; Ruzanna & Marhani, 2008). On top of that PWD's research in Malaysia is more towards profiling and the development of the mental health field as a whole (Chong et al., 2013; Mohamad et al., 2012).

Furthermore, past research on caregivers with a person with intellectual disabilities only highlights more on caregivers' burden (Domínguez-Vergara et al., 2023; Bahry et al., 2019; Chou et al., 2011; Nam & Park, 2017). Another related study on caregivers and disabilities identifies strategies for minimizing and maximising access to facilities and comparing them with non-disabled children (Bahry et al., 2019). Thus, these highlight the difference between this study other available studies

and highlight the need for this study as it focuses on the impacts of caregivers caring for PWD and how they can overcome the impacts through their coping strategies, social support and needs of the caregiver caring for PWD.

In referring to the Mid Term Review of Malaysia's Eleventh Plan, Second Pillar, Enhancing Inclusive Development and Wellbeing, a more significant commitment is emphasize as a necessity to address the needs of persons with disabilities in Strategy A4, "Addressing the Needs of Specific Target Groups". The mentioned strategy highlighted the importance of parents and caregivers equipping themselves with the necessary parenting development knowledge and skill to raise their children.

In Malaysian settings, in most cases, parents or caregivers of children with disabilities depend on Community Based Rehabilitation (CBR) centres to consult and obtain services regarding their children's needs, thus creating dependency towards CBR centres. Due to reducing reliance towards CBR, Universiti Sains Malaysia (USM), using their Division of Industry and Community Network (BJIM), initiated a dialogue with USM staff's among those with children with disabilities on 14th March 2019. They discovered that USM has up to 70 staffs with children with disabilities, and the need for an inside campus CBR was highlighted. In regard to this matter, USM initiated the opening of an inside campus CBR with the support of the School of Social Sciences, Division of Industry and Community Network (BJIM), and Malaysia's Department of Social Welfare (JKM). This completes one of USM's initiatives to support USM staffs to improve services for staff who has children with disabilities. The informants of this study are parents and caregivers of children with disabilities currently benefitting from the USM's CBR. This also indicate the added value of this study as only caregivers who are equipped with the Training of Trainers (ToT), which

indicates more caregiving experience for the parents and caregivers caring for persons with disabilities participated in this study. Similar to training of Trainers (ToT) approach, WHO's Caregiver Skills Training Program (CST) for families of children with disabilities to also highlighted caregivers are able to learn skills to support their children's social communication, adaptive behavior and reducing their challenging behavior through experiencing this types of training (Salomone et al., 2019). ToT approach promotes more inclusivity, especially in early childhood education and care, that is possible to be scaled up to be used as a national program (Soni et al., 2020).

Thus, this study is seen to be able to explore the impact of caregivers caring for PWD and analyses how does caregivers cope with the impact of having PWD in families. Furthermore, this study analyses whether the current social services and social support system assist caregivers with PWD in families and the needs of caregivers caring for PWD in their families. Finally, the researcher suggests and develops a relevant social work practice and intervention model for caregivers with PWD.

1.4 Research Questions

The primary purpose of this study is to understand the lived experience faced by caregivers of persons with intellectual disabilities (PWD). This ultimately aims to contribute to developing a more strategic and practical framework of social work intervention for caregivers caring for Persons with Intellectual Disabilities (PWD) in Malaysia.

i. What is the impact of caregiving towards caregivers caring for PWD?

ii. How do caregivers cope with the impact of caring for PWD?

iii. To what extent does the current social support system assist caregivers caring for PWD?

iv. What are the needs of caregivers caring for PWD?

1.5 Research Objectives

Specifically, the primary objectives of this study are:

i. To explore the impact on caregivers caring for PWD.

ii. To analyse coping strategies of caregivers caring for PWD.

iii. To analyse does the current social support system assist caregivers caring for PWD.

iv. To identify the needs of caregivers caring for PWD.

v. To suggest and develop a relevant social work intervention model for caregivers caring for PWD.

1.6 Significant of Study

Firstly, the significant of the study is to create awareness of the issues and challenges among Malaysians caregivers with PWD. This gives them greater priority and support from governmental and non-governmental bodies. Furthermore, this study also promotes new and additional knowledge on PWD and their caregivers in the aspect of new empirical knowledge and research.

The study also suggests relevant social work interventions model for caregivers of PWD. This includes a suggestion on coping strategies for caregivers for PWD facing issues and challenges in caring for PWD. The suggestion is significant because it is derived from the experience of a caregiver caring for PWD.

In addition, this study enables other family members or community involved with caregivers caring for PWD to better empathize with their struggles. This can create better opportunities and accessibility for caregivers with PWD, particularly regarding psycho-social support. This study can act as an advocacy tool for PWD and

their families to promote new ideas to policymakers and the relevant institutions on what they feel needs improving.

Furthermore, the existence of this study helps key figures in the field on what is needed most by caregivers of PWD. The empirical data and analysis can help convince key figures from governmental and non-governmental agencies to contribute towards caregivers of PWD. This also creates more awareness of mental health and related illnesses (Hatfield et al., 2005; Gee et al., 2015; Hanafiah & Bortel, 2015).

The significance of this study is to help improve existing policies or promote new acts that involve caregivers with PWD. The study also helps support the relevances of existing acts such as the Persons with Disabilities Act 2008 and the Mental Health Act 2010. The improvement and promotion of existing policies must be aligned with the legal framework to ensure it can be governed and committed towards and align with the research objectives and question of the study.

Besides, this study also contributes to the knowledge and contribution in the field of social work. According to Krysk dan Finn (2007), social work researchers often use their research outcomes to uplift the scientific status of social work. The study can be a good learning tool to help improve the social conditions of the clientele.

Lastly, this study is significant because, according to Krysk dan Finn (2007), the function of social work research promotes the usage of scientific methods in identifying the existence of a social problem. An upcoming researcher can use this study as a reference to explore further the gaps or other scopes that were not covered in the study. The outcome of the study raises the accountability of the client through numerous assessment programmes while maintaining good communication and increased accessibility towards existing sources to help the client. This study can also be a good foundation for future study.

1.7 Scope of Study

Whilst the lived experienced of caregivers caring for persons with intellectual disabilities have been well explored and researched throughout the years, the impact, coping strategies, social support, and needs of the caregivers has been undermined. The aim of this study is to understand the lived experience faced by caregivers of persons with intellectual disabilities (PWD) and to contribute to developing a more strategic and practical framework of social work intervention for caregivers caring for Persons with Intellectual Disabilities (PWD) in Malaysia.

The scope of this study is restricted to 18 caregivers caring for person with intellectual disabilities (PWD) who has gone through Training of Trainers (ToT) in CBR USM Main Campus. Usage of the Training of Trainers (ToT) approach on caregiving by the caregivers, which indicates more caregiving experience for the caregivers caring for persons with disabilities highlights additional lived experienced in terms of skills to support their children's social communication, adaptive behavior and reducing their challenging behavior (Salomone et al., 2019).

Only caregivers who is the head of the family or act as a decision-maker aged 18 years and above are selected in the study. 18 caregivers were selected after researcher has reached saturation in data collection process which highlighted why researcher stop data collection process at 18 informants. From this example we can see that the scope of the study has placed a limitation on the sample size and a limitation by only opening recruitment to caregivers that has attended the ToT training from CBR USM's Main Campus. Caregivers caring person with intellectual disabilities that are not applied to these limitations are excluded from this study.

The scope of this study is key in interpreting the results of this study as caregivers who are recruited in this study, they reflect different lived experiences after attending the ToT training compared to those who did not.

1.8 Chapters Summary

This chapter contains an introduction and background to the main topic of the study. Statistical data designed to create an overview of the study are also presented in this topic. Statistics on PWD and their impacts on caregivers are introduced in this chapter. Furthermore, the study's problem statement, along with its research questions and objective, are also elaborated. The chapter closes with an explanation of the significance of the study, scope of the study, and a brief summary of every chapter in the thesis.

The next chapter covered a comprehensive literature review of the thesis that generally involved a study on PWDs in Malaysia and their impact on caregivers and families. The chapter also discusses relevant studies involving PWD and caregivers. Social work practice in the context of disability, theoretical and conceptual framework are discussed as well in chapter two. All the literature is designed to ensure that they coincide with the research questions and objectives.

Chapter three elaborated more on the research methodology of the study. The study's research design, population, sample, and rationale are elaborated in chapter three. The research instrument, location, data collection and analysis procedure are explained in detail in the chapter. The chapter closed with an elaboration on the pilot study, the validity and reliability of the research and the ethical considerations of this study.

Chapter four presented the findings of the study based on data collected from research informants. Information on research informants' socio-demographic

background are elaborated in detail in this chapter. Data from the study are analysed. The narrative presentation can be identified in this chapter because the data source relied on in-depth interviews. Overall, chapter four covered research findings based on the impact of caregiving, coping strategies of caregivers, social support and needs of caregivers caring for PWD. Reported research findings are also based of research objectives.

Finally, an elaborate discussion of research findings is discussed in chapter five, the final chapter. This chapter thoroughly discussed research findings based on the impact of caregiving, coping strategies of caregivers, social support and needs of caregivers caring for PWD critically and comprehensively. Research findings are discussed from theoretical perspectives, past studies, socio-cultural context, social services systems and the researcher's observation during the in-depth interview. This chapter also suggests relevant intervention model and social work services for caregivers caring for PWD. Implications on social work practice, education, policies and law are covered as well in this chapter. Finally, research limitations, future studies and a conclusion are presented.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter reviewed past literature related or in significance to the topics of this study. The literature review creates foundational knowledge for those unfamiliar with the research topics. Each component of the research study was taken and reviewed to gain more knowledge and understanding regarding completing this research. Some of the issues included understanding disability in Malaysia, the impact of caregivers caring for PWD, coping strategies of caregivers caring for PWD, the social support system for caregivers caring for PWD and the needs of caregivers caring for PWD.

The literature review is done thoroughly and accordingly to develop quality knowledge that acts as the basis of knowledge towards the development of this study. Furthermore, the theoretical and conceptual framework of the study are also discussed in this chapter. The theoretical framework was supported by family system, ecological, and stress theories. Lastly, the conceptual definition of relevant terms in this study are also explained and elaborated.

2.2 Definition and Classification of Disabilities

The Malaysian government recognises people with disabilities (PWDs) as those who have a long-term physical, mental, intellectual, or sensory impairments which in interaction with various social and environmental barriers, may hinder their full and effective participation in society (Laws of Malaysia, Persons with Disabilities Act, 2008). Although there is no single definitive legal or policy framework for classifying people with disabilities across all sectors, the Malaysian Ministry of Women, Family and Community Development (MWFCD) has developed a disability

categorisation system to enable them to effectively register Malaysian adults and children with disabilities.

The seven categorisations within the Ministry's classification framework are hearing disability; visual disability; speech disability; physical disability; learning disability; mental disability; or 'other' disabilities, which includes children with multiple disabilities or those for whom the other categories are not suitable (UNICEF, 2014). Developments of disability in Malaysia at this time were part of a broader global disability terminology. Thus, the Washington Group sought to challenge medical definitions of disability and measurement and promote definitions that were standardised, culturally neutral and rooted in a rights-based approach to disability under the guidance of the United Nations.

Persons with Intellectual Disabilities (PWD) included two of the seven categories within the Malaysian Ministry of Women, Family and Community Development (MWFCD) framework: learning disability and mental disability. This is because intellectual disability can be defined as a significantly reduced ability to comprehend complex information and learn and adapt new skills into their daily living skills. This impairment usually results in decreased social functioning and problem-solving ability, which affect them before approaching adulthood, and have a lasting effect on personal development (American Psychiatric Association, 2017: World Health Organization, 2020).

2.3 Understanding Cultural Perspectives of Disability

Beyond typical well-acknowledged understandings of disability, the cultural definition of disability conception, perception, recognition, labelling, classification and treatment should also be recognised (Kleinman, 1977a; Kleinman, 1977b; Ng, 1997). According to Ling (2007), a study in Sarawak reinforces that multicultural

diversity in Malaysia generates a complex nature of disability acceptance in the nation. Further study suggests understandings of disability were embedded in components of religion and spirituality. For example, major differences were determined between Malay and traditional Chinese beliefs (Geok, 2012). According to Geok (2012), a study in Sarawak investigating the quality of life of mothers with Down syndrome has found that amongst Muslim mothers, there was a strong sense of acceptance towards the child as their religion portrays that their child was a predestined gift from God. The situation is different from Chinese families as they attribute their children's disability to something they did wrong in a previous life (Geok et al., 2013; Ling, 2007). However, a study also suggested that both Malays and Chinese in Malaysia consider the social and psychological aspects of disability are higher than any religious or cultural causes (Edman & Koon, 2000). Thus, this creates a different dimension and approach towards the perception of persons with disabilities in Malaysia. The contradictory nature of acceptance towards children with disabilities are heavily influenced by the cultural approach of certain values or belief.

In Malaysia, religious convictions about disability have been juxtaposed by local cultural beliefs that foster negative impacts on caregivers and families of PWDs in various scenarios. For example, cultural views on the perception towards mothers that gave birth to children with disabilities are punishment for their past mistakes or bad conduct during the child's pregnancy (Geok, 2012). The same perception is shown amongst Iban communities in East Malaysia that relates a child’s disability to the behaviour of mothers during pregnancy (Mamba, 2010).

In addition, among Asian countries especially Chinese populations share cultural values exist and Confucian teachings of self-cultivation. Thus, they traditionally believing in bad Karma contributes to disability being viewed as a

manifestation of ancestors' past moral misconducts and contributed to stigma and discrimination towards PWDs and children with disabilities across the continental landmass (Ngo et al., 2012). This impacts the level of acceptance not just from the communities towards PWD but from the caregivers themselves. Understandings of illness, disability and behaviour in most traditional Asia societies are still rooted in their local belief systems. Thus, the preferential approach towards treatment is mentioned in the domain of a traditional spiritual healer (Botros et al., 2006; Lauber & Rössler, 2007). Disability or other chronic illnesses are often viewed as a manifestation of a spiritual penalty for being involved in witchcraft or wizardry, or due to a demon possession through ancestral inheritance of misconduct or any other social and moral transgressions (Lauber & Rössler, 2007).

The range of religions, ethnicities and languages in Malaysia multicultural landscape, generate a diverse and intertwining definition regarding disability (Sheri, 2015; Ling, 2007). This creates plenty of different and complex interpretations and understandings of disability whether in Malaysia or other part of the globe.

The number of registered persons with disabilities (PWDs) in Malaysia has significantly increased compared to the past three years. A staged increase from the year 2016 to 2018 have shown that within the three years, the total sum of PWD's registration has increase from 50,000 a year to 150,000 in the past 3 years (Jabatan Kebajikan Masyarakat, 2018). However, the voluntary nature of the PWD registration in Malaysia still unable us to determine the actual figure (Boardman et al., 2012; Mohamad et al., 2012; Steffen et al., 2009). The rise in the number of registration as we can be seen in Figure 1.1 below.

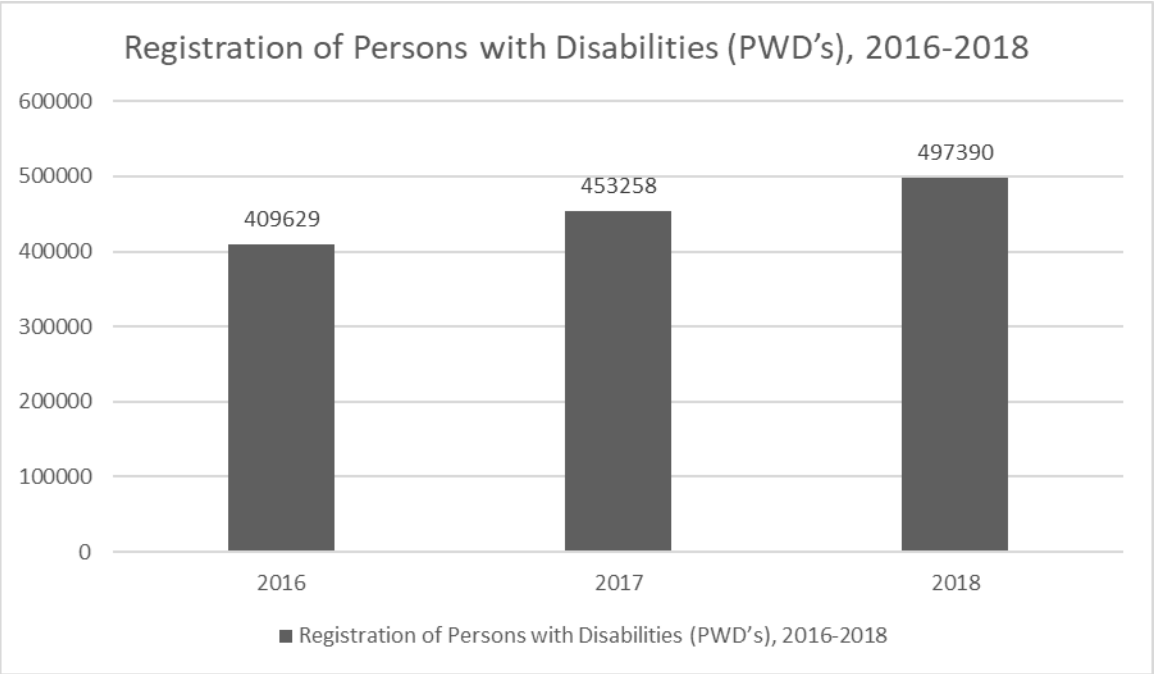

Figure 1.1 Registration for PWD in Malaysia 2016-2018

Source: Jabatan Kebajikan Masyarakat 2018

From the year 2009, there are seven categories of PWDs in Malaysia. Two out of the seven categories consist of intellectual disabilities; they are persons with learning disabilities (PWLD) and persons with mental disabilities (PWMD). Currently, as of 2018, learning disabilities and mental disabilities comprise 34.2 percent and 8.3 percent, respectively, of the total of PWDs in Malaysia (Jabatan Kebajikan Masyarakat, 2018). This shows that PWD consist of 42.5 percent of the total of PWDs in Malaysia, which is the highest percentage for the percentage of PWDs. Figure 1.1 shows the percentage of PWDs by category of disabilities in Malaysia.

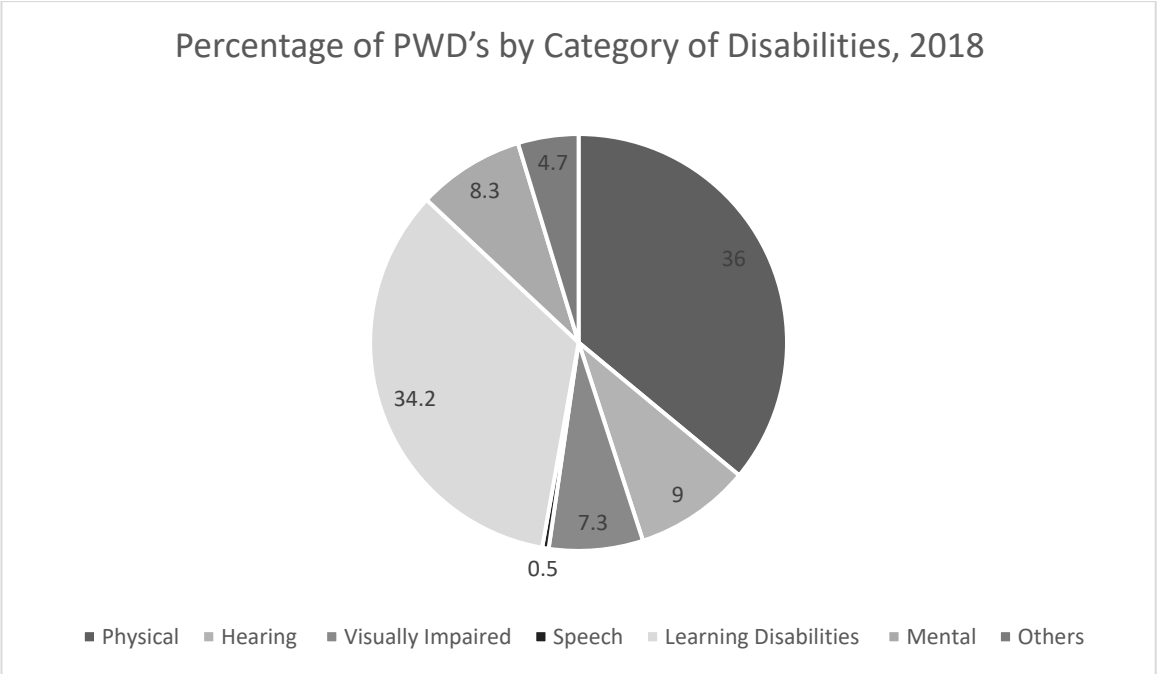

Figure 1.2 Percentage of PWD's by Category of Disabilities

Source: Jabatan Kebajikan Masyarakat 2018

PWMD is one of the latest categories introduced in 2009 (Anon, 2009). According to statistics, the number of PWMD has risen from 29,403 in 2015 to 41,268 in 2018 (Jabatan Kebajikan Masyarakat, 2015; 2018). The same goes for PWLD. The numbers increase from 127,987 in 2015 to 170,269 in 2018 (Jabatan Kebajikan Masyarakat, 2015; 2018). The registered PWMD consists of 725 children and 40,493 adults from 41,268 as of 2018, while the population of registered PWLD stands at 124,807 children and 45,462 adults from 170,269 as of 2018 (Jabatan Kebajikan Masyarakat, 2018).

The significant increase in the numbers of PWMD and PWLD proves that the numbers of caregivers caring for them should also have risen. Thus, more attention towards supporting PWD and their caregivers must be given. Even though mandatory registration has not been implemented in Malaysia, PWDs in Malaysia are encouraged to register to portray a more accurate numbers of representation of PWDs in Malaysia

(Boardman et al., 2012; Mohamad et al., 2012; Steffen et al., 2009). This is important to push for greater acknowledgement and empowerment for PWDs.

Furthermore, according to Jabatan Kebajikan Masyarakat (2020), the definition of PWMD from Persons with Disabilities (PWD) Act 2008 (Act 685) can be defined as those who are experiencing chronic mental illness which limits them to function or partially function in the society entirely. For someone to be considered a PWMD the must have been treated or received psychiatric treatment for a minimum of two years. The level of social, cognitive and behavioral functioning must be determined by a psychiatrist to be categorised as PWMD. Types of mental illness that PWMD are having are Neurosis (Minor), Psychoses (Major) and mental disorder (Malaysian Mental Health Association (MMHA), 2020).

In addition to that, the definition of PWLD from Persons with Disabilities (PWD) Act 2008 (Act 685) can be defined as those who a series of tests have tested, observation and inspection by recognized experts from a government facility for experiencing issues or difficulties in learning (Jabatan Kebajikan Masyarakat, 2020). This often occurs due to an individual's lack of cognitive or intellectual capabilities. Types of learning disabilities include Global Development Delay (GDD), Down Syndrome, Attention Deficit Hyperactivity Disorder (ADHD), Autisme, Dyslexia, Dyscalculia, and Dysgraphia (Ministry of Health Malaysia, 2011).

The significant increase in PWD numbers suggests that intellectual disabilities truly become the second public health issue in Malaysia after heart disease (Ministry of Health Malaysia, 2015). Efforts and support for this community has to be increased as their quantity grows.

2.4 Prevalence of Disability in Malaysia

According to UNICEF's State of the Worlds Children's Report (2013), statistics that capture data on all children, including those who are disabled, gathering statistical figures are important in achieving an equitable society. However, to be included, a child must be visible and counted. Therefore, proper data collection and analysis are vital for ensuring that children with disabilities are included in enhanced statistical research and disaggregation of data (UNICEF, 2013). However, obtaining credible data and information on children with disabilities in Malaysia continues to be challenging. This is because the lack of a comprehensive and structured system of data collection is compounded by the weak relationship between registration and service provision (Amar-Singh, 2008).

The initial detection of disabilities in children is coordinated by the Department of Social Welfare (DSW); the Ministry of Health (MOH); and the Ministry of Education (MOE) of Malaysia. Each entity collects and maintains distinct streams of data on children with disabilities; the respective data sets have never been collated. The inability of the mentioned above government agencies to collaborate on classifying data creates complications and errors in representing accurate figures. This has led to international and national pressure to integrate data collection systems.

According to Islam (2015), in Malaysia, registration of disability is not compulsory. Therefore, persons with disabilities (PWDs) register their details voluntarily without any obligation. Thus, this contributes to the incomplete and misrepresentation of statistics on disability (Islam, 2015). According to the department of social welfare, the number of people registered as disabled in Malaysia increased from 409,629 in 2016 to 497,390 in 2018, marking an increase of 87,761 registrations over the course of three year (Jabatan Kebajikan Masyarakat, 2018). Based on these