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Disability and Gender in the Global South: The Lived Experiences of Disabled Women in Malaysia

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Abstract

Disability is argued to have some relation to gender and culture. However much disability and gender research is based on data collected in the Global North, and little is known about disabled women in the Global South. This thesis therefore sets to explore how disabled women in Malaysia experience their lives. Malaysia is a multi-ethnic and multi-religious country located in the heart of South East Asia. It is now recognised as an upper-middle income country but was previously considered as a lower income country following its independence from Britain in 1957. Although the Malaysian government has developed significant disability provision, policies and legislations since the period of colonialism, disabled people still encounter major barriers in many aspects of their lives. More importantly research involving Malaysian disabled women is very limited and this study seeks to fill the gap.

The data of this study was collected from in-depth interviews with 33 Malaysian women with physical (mobility) impairment. Over a period of 6 months, 17 Malays, 8 Chinese and 8 Indian women were interviewed twice in Malaysia. The majority of women came from low-income and rural families and thus many of them had limited access to basic living needs; such as healthcare, transportation, education and training, as well as employment. Nevertheless the findings demonstrated that many women were not only marginalised from wider social and economic participation because of financial and location factors, but their situation was exacerbated by complex interactions between individual, familial, sociocultural and gender factors. These were reinforced by the inadequacy of disability support, services and legislation emanating from the state; as well as a general negative cultural conception of disability and women in Malaysia. The data also revealed that many women were subjected to exploitation, violence and abuse by men in various life settings.

The complex intersections between disability and gender experiences prevented these women from becoming active independent social agents in a disabling and patriarchal society. Many women faced constant challenges in exercising their agency in both private and public life that significantly related to structural and attitudinal barriers, as well as being the result of the powerful influence of family, culture and religion. Therefore all these factors undermined the wellbeing of disabled women, restricted their full potential, and denied their rights to be equally included in Malaysian society.

Whilst the study employed the feminist and critical realist approaches, the thesis suggests undertaking an alternative framework of feminist research which is culturally sensitive i.e. Islamic feminism for a local perspective. Keeping with the socio-historical context of the country where the majority of people are Muslim, the Islamic feminism may offer a useful framework of research for the understanding of disability and gender experiences in Malaysia. The study proposes that the state employs both the politics of redistribution and the politics of recognition to challenge the pervasive social injustice experienced by Malaysian disabled women. Equally important the thesis advocates that the state and women's activists take all appropriate measures in protecting disabled women from exploitation, violence and abuse in both the private and public spheres. The thesis concludes by addressing the research limitations and its implications for future research.

Table of Contents

List of Figures and Tables

Acknowledgments

بِسْمِ ٱللَّٰهِ ٱلرَّحْمَٰنِ ٱلرَّحِيمِ

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Aizan Sofia Amin

Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Aizan Sofia Amin

Abbreviations

CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
DBKL	Kuala Lumpur City Hall
DSM	Department of Statistics Malaysia
DSW	Department of Social Welfare
EPC	Disabled Employee Allowance (*Elaun Pekerja Cacat*)
JICA	Japan International Cooperation Agency
MCD	Malaysian Confederation of the Disabled
MOE	Ministry of Education
MOH	Ministry of Health
MOHE	Ministry of Higher Education
MOHR	Ministry of Human Resource
MTUC	Malaysian Trade Union Congress
MUWHLG	Ministry of Urban Wellbeing, Housing and Local Government
MWFCD	Ministry of Women, Family and Community Development
NGOs	Non-governmental organisations
OKU	*Orang Kurang Upaya* (disabled persons/people)
PLPP Bangi	Bangi Industrial Training and Rehabilitation Centre
PWD	Persons with disabilities
PWDA 2008	Persons with Disabilities Act 2008 (Act 685)
SPOKU	Registration System for Persons with Disabilities
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNHRC	United Nation Human Rights Council
UNICEF	United Nations Children’s Fund
UK	United Kingdom
US	United States
WAO	Women’s Aids Organisation
WHO	World Health Organisation

Transcription Notations

Notation	**Definition**
[word]	Material within brackets represents the transcriber's clarification of an unclear part, or a change made to preserve anonymity.
[…]	Indicates that material has been omitted from the text.
…	Indicates a short pause, typically no more than one-tenth of a second.
Italics	Italics used to indicate non-English words.
(word)	Material within brackets represents the participant's emotions.
X	A place name which is made confidential.

Introduction

The World Health Organisation (WHO) and the World Bank in their *World Report on Disability* estimate that over one billion or 15 percent of the world population have some form of disability (WHO, 2011a). From this global estimate, the prevalence of disability is more common amongst the poor and higher in lower income/developing countries where 80 percent of disabled people live (WHO, 2011a). While the incidence of disability is higher in developing countries or the Global South, empirical research involving disabled people from this part of the world is scarce (Grech, 2009; WHO, 2011a; Shakespeare, 2012). Globally disabled people experience greater socioeconomic disadvantages:

> Across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities. This is partly because people with disabilities experience barriers in accessing services that many of us have long taken for granted, including health, education, employment, and transport as well as information. These difficulties are exacerbated in less advantaged communities (Chan and Zoellick, 2011: xi)

More importantly disability is found to be more widespread amongst women than men (WHO, 2011a). The Global Burden Disease and the World Health Survey both estimate that females have a higher percentage of disability than males (WHO, 2011a). This indicates that the Global South countries such as Malaysia may observe a higher percentage of disability amongst women than men. However research involving Malaysian disabled women is very limited and little is known of how they experience their lives. This study therefore sets out to provide empirical evidence regarding disability and gender experiences in Malaysia.

Although disability is a global phenomenon, it is argued to have some relation to gender (Morris, 1999; Thomas, 1999) and culture (Shakespeare, 1994; Ingstad and Whyte, 1995; Coleridge, 2000; Riddell and Watson, 2003). Disability therefore cannot be reduced to a universal experience as it may be perceived and experienced differently across societies as it is influenced by cultural variables. This suggests that in order to obtain a full understanding of disability and gender experiences the study should be conducted within a local context;

incorporating the economic and socio-historical assumptions, and the circumstances of a particular society:

> When we talk of women with disabilities, we need to take into account the historical and contextual dimensions. Women with disabilities who live in cities have different experiences from their rural counterparts and women who live in the Global South experience more hardship than those in the mainly rich nations of the Global North (Frohmader and Meekosha, 2012: 289)

Whilst disabled women across the globe may experience their lives differently, they are generally subjected to greater and more numerous disadvantages than disabled men. They are not only encounter disabling barriers but also gender discrimination (WHO, 2011a). Females of all ages with any type of disability are recognised to be amongst the most vulnerable and marginalised group in society (United Nations General Assembly, 2000). Despite this feminist disability writers argue that the issues of disabled women have been neglected within disability studies and feminist theories (see, for example, Morris, 1993; Begum, 1992; Thomas, 1999; Garland-Thomson, 2002; Ghai, 2002). It is important to incorporate the agenda of disabled women into disability and feminist research so that they will not be excluded from the mainstream society.

> Disabled […] women – have little opportunity to portray our own experiences within the general culture, or within radical political movements. Our experience is isolated, individualised; the definitions which society places on us centre on judgements of individual capacities and personalities. This lack of a voice, of the representation of our subjective reality, means that it is difficult for non-disabled feminists to incorporate our reality into their research and their theories, unless it is in terms of the way the non-disabled world sees us (Morris, 1991: 8).

Likewise in the countries of the Global South, such as Malaysia, disabled women are often absent within disability and gender writings. For example in other Asian countries like India, Anita Ghai argues that disabled women are often underrepresented within the Indian disability and feminist works and she advocates integrating disabled women within both disability and women's movements (Ghai, 2002). For that reason it is vital to include the issues of Malaysian disabled women into the mainstream agendas to ensure that they are not marginalised from developmental programmes; both at the national and international level.

Therefore this thesis endavours to explore the lived experiences and aspirations of the Malaysian disabled women that took part in this study. This research emerged out of my own experiences as a Malaysian disabled woman. Coming from a low income family and raised in rural area, I experienced significant barriers in various life settings as a result of my disability. Nonetheless I managed to overcome those challenges and had promising life prospects despite having had to ‘battle’ substantial negative life encounters with others. As such I was keen to discover how other disabled women in Malaysia experienced their lives and whether they had the opportunity to explore their potential and exercise their agency in their family and society. Drawing from my own experiences, and through direct contacts with the Malaysian disabled women, it became clear that they had experienced pervasive social injustice in both the private and public spheres. Thus, the aspiration of this thesis is that this study will hopefully grant these women justice by enabling their voices to be heard at the local and national, as well as international, levels.

Structure of the thesis

The thesis consists of two literature chapters; a methodology chapter describing the theoretical frameworks and methods used for data collection; four data chapters, and finally concludes with a discussion chapter as outlined below.

Chapter 1: *Disability and (Disabled) Women in Malaysia* provides a brief overview of Malaysia and explores a detailed account of disability and women in Malaysia. The chapter offers a socio-historical background of Malaysia in terms of its location, history, economics, politics, people and culture. The chapter then focuses on the history of disability welfare in Malaysia since the colonial period until the present day. The discussion then moves on to the development of disability provision, policies and legislations as well as outlining some major challenges experienced by disabled people in Malaysia. The final part explores six main issues relating to disabled women in Malaysia in terms of gender norms, access to healthcare, education and training, economic participation, violence and abuse; as well as participation in politics and public life. However research involving disabled women in Malaysia is very limited and therefore the discussion focuses on available research on Malaysian women in general and disabled women elsewhere.

Chapter 2: *Conceptualising Disability in the Global South* explores the underlying issues involved in theorising disability in developing countries (Global South) with specific reference to disability theories and research in developed world (Global North). The chapter examines three major issues which are prevalent in understanding disability in the Global South; such as disability definitions, disability prevalence, and its relation to poverty. This chapter goes on to discuss the fundamental principles of the social model of disability, its critiques and new approaches. The chapter finally looks at an alternative framework of disability research that focuses on the critical realist approaches. The critical realism is argued to offer a non-reductionist perspective on disability research that allows for a complex level of analysis into disabled women's lives in the Global South countries like Malaysia.

Chapter 3: *Methodology* comprises of the theoretical approaches and methods employed in the study. The chapter begins with discussion on the theoretical frameworks that looks into the historical development of disability research in the Global North which may influence disability research in the Global South; such as the positivist research approach and emancipatory research paradigm. The feminist and critical realist approaches are explored as alternative research frameworks to the emancipatory research paradigm. The chapter then examines the research designs used in this study which employed full qualitative and narrative research methodology. It also outlines the ethical considerations and participants' recruitment strategies as well as discusses the research methods used; such as qualitative interviewing, research diaries and field notes. The chapter also provides a detailed description of the stages of fieldwork and data analysis and management. Finally it explores some of the challenges involved in conducting cross-cultural research using multiple languages a scenario which led to translation issues and dilemmas.

Chapter 4: *Experiencing Disablement*, the first data chapter, explores the main challenges and issues experienced by the research participants. The chapter observes that the majority of participants were affected by two main factors in experiencing disablement which related to poverty and rurality factors. These two main themes, including the inadequacy of disability support from the welfare state, played crucial roles in determining how far the women interviewed had access to healthcare, transportation, education and training, employment, housing, and family life. The chapter shows that understanding the lived experiences of Malaysian disabled women involved complex analysis that included not only the financial and rurality factors but also the structural barriers, attitudinal barriers, impairment, gender issues and cultural norms. The chapter concludes that the majority of women were systematically excluded from wider social and economic participation in society which resulted from the interaction between multiple factors, causing them to experience 'psycho-emotional disablism' in a complex manner.

Chapter 5: *Family* discusses the vital role family played in supporting the needs of the majority of participants. The lack of disability support from the welfare state, as discussed in Chapter 4, reinforced a strong dependency on family as the primary carer. Such a notion of traditional care based on mutual understanding and interdependent relationships within family will be explored from the framework of a feminist ethic of care. Although the family provided the most support to disabled women, the powerful influence that family had on these women often undermined their sense of self and autonomy. The chapter therefore looks at how the women experienced care within or outside their familial environment, observes how they negotiated their identities within familial relationships and examines how gender roles had a crucial impact on them and their family.

Chapter 6: *Love, Marriage and Motherhood* explores how the participants sought to have a romantic relationship - or not - and how they experienced love, marriage and motherhood. The women's attitudes and perceptions towards love, marriage and motherhood were determined by the cultural norms of Malaysian society which highly values traditional gender roles and the importance of family. This chapter discovers how many of the participants were denied their rights to have a family life due to the negative cultural conception of disability and women in Malaysia. The chapter highlights the significant barriers and challenges these women faced in seeking to fulfil their quests to become partners, wives and mothers in a patriarchal and disabling society. Not only that but this chapter uncovers how some women were subjected to domestic violence and abuse perpetrated by their partners.

Chapter 7: *Identity Constructions* builds upon the narratives presented in Chapter 5, 6 and 7 and focuses, in more detail, on how the participants constructed their identities. This final data chapter observes how the participants formed, reformed, and negotiated their self-identities through social interactions with others. The chapter discloses that the participants had few opportunities for self-affirmation due to oppressive and discriminative societal attitudes toward them. Despite such challenges, some women were able to exercise their agency through employment, independent life and disability activism. This chapter ends by highlighting some interesting findings that look at how the majority of participants across ethnic groups identified their disability identity as containing positive aspects within the context of religion.

Chapter 8: *Discussion and Conclusion* outlines the major themes and implications of the preceding data chapters. This final chapter begins by presenting a full summary of the research findings. The chapter moves on to establish three major themes that emerged from the study. The first theme looks at the link between poverty, rurality and impairment. The second theme observes the influence of gender. The third theme examines the intersection of family, culture and religion. This chapter then suggests some implications for disability theory, policy and practice in Malaysia. Whilst the study proposes that the feminist and critical realist approaches provide the most fruitful framework for disability and gender research in Malaysia, the mainstream feminist approach may not be suitable for application within a local situation. Therefore an alternative approach of research that is more culturally sensitive, such as that of Islamic feminism, is suggested to provide a useful framework for disability and gender research in Malaysia. The chapter also suggests two implications for the wellbeing of Malaysian disabled women that focus on the politics of distribution and recognition, as well as protection from exploitation, violence and abuse. This chapter concludes by discussing some limitations of the study and its implication for future research: it also contains section of self-reflection in regard to the study.

Chapter 1: Disability and (Disabled) Women in Malaysia

1.1 Introduction

This chapter aims to provide a background for the study and is divided into three parts. The first part gives brief details of Malaysia in terms of its location, history, economics, politics, people and culture. The second part explores disability in Malaysia, with a particular focus on history of disability welfare, the development of disability provisions, policies and legislation, and also the major challenges experienced by disabled people within a Malaysian context. The final part discusses the main issues relating to (disabled) women in Malaysia (and elsewhere) with specific reference to gender norms, access to healthcare, education and training, and economic participation, violence and abuse, as well as participation in politics and public life.

1.2 Malaysia overview

Malaysia is known as an upper-middle income country (The World Bank Group, 2013). It is located in the heart of South East Asia and its closest neighbours are Singapore, Thailand, Indonesia and Brunei. Geographically Malaysia is divided into two regions, Peninsular Malaysia (West Malaysia) and Borneo (East Malaysia), which are separated by the South China Sea (see Figure 1.1). It has 13 states and three Federal Territories with Kuala Lumpur as the country's capital, Putrajaya as the administrative government capital, and Labuan as the offshore international financial centre (Ministry of Federal Territories and Urban Wellbeing, 2010).

Figure 1.1 Map of Malaysia

(Source: CIA World Factbook, 2011)

According to the 2010 Census, the population of Malaysia was 28.3 million people of which the majority, 22.5 million, live in the Peninsular Malaysia; while only 5.8 million people reside in Borneo (Department of Statistics Malaysia, 2011). Malaysia, formerly known as Malaya[1], has a very long history of colonisation by several parties (Portuguese, Dutch, Japanese and British) from the year 1511 until 1956. It achieved independence from Britain on 31 August 1957 (Malaysia National Library, 2000).

As a result of the colonial era; Malaysia became a multi-ethnic and multi-religious society (Green and Rowell, 2001; Kamal Hassan, 2005). The dominant ethnic group is Malay[2] (51 percent) followed by Chinese (27 percent), Indian (12 percent), indigenous people (12 percent), and other ethnic groups (two percent) (Department of Statistics Malaysia, 2011). Islam is the official religion of the country (60 percent of the population are Muslims) but other religions (e.g.

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[1] Malaya is the former name of Malaysia. It was restructured as the Federation of Malaya in 1948 before its independence. On 16 September 1963, Malaya united with North Borneo, Sarawak and Singapore to form a new country of Malaysia. However in 1965, Singapore became independent from Malaysia.

[2] The Malays and indigenous people are classified as 'Bumiputera' (son of the soil or people of the land), and are given certain privileges by the government, mainly in employment and education (Milne & Mauzy, 1999:1). Article 160 of the Constitution of Malaysia, it stipulates a Malay must be a Muslim.

Buddhism, Christianity, Hinduism, and others) are also practised freely by the people (Kamal Hassan, 2005). The national language is the Malaysian language[3] but English is also widely used, especially in business, administration and education, whilst at the same time different ethnic groups have their own mother tongue. The literacy rate for amongst young people in 2010 was 98.9 percent (UNESCO-UIS, 2013). Malaysia is governed by a constitutional monarchy employing a Parliamentary legislation guided by the Constitution of Malaysia. The Constitution of Malaysia has a unique dual justice system: the secular laws (criminal and civil) and the sharia laws (Islamic laws)[4].

Females represent about 48.8 percent and males account for 51.2 percent of the whole population. The number of females in the Malaysian population is almost equivalent to the male population with the overall gender ratio being 100 females for every 106 males. Life expectancy at birth for females (76.6 years) however is higher than for males (71.7 years). The infant mortality rate was gradually decreased from 66.1 per 1000 live births in 1960 to only 5.7 per 1000 live births in 2009 (World Bank, 2011). The current trend also indicates that in Malaysia the structure of the populace suggests a trend towards an ageing population (Department of Statistics Malaysia, 2011) paralleling the rapid ageing of the world population (WHO, 2013).

1.3 Disability in Malaysia

As a post-colonial country, Malaysia has undergone significant improvements and transformations in disability welfare since the period of imperialism. Currently the primary welfare provider is the Department of Social Welfare (DSW) under the Ministry of Women, Family and Community Development (MWFCD). The role of the DSW and support for disabled people will be discussed throughout this chapter. Other ministries such as the Ministry of Health (MOH), Ministry of Education (MOE) and Ministry of Human Resource (MOHR) are also responsible for

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[3] The government chose Malay as its national language at independence. However, the racial tensions of the sixties spurred the government to rename the national language as the Malaysian language (Bahasa Malaysia) (Asmah, 1992: 157).

[4] Sharia law only applies to Muslims in the areas of personal status, marriage and family relations (UN Women Regional Office for Asia and the Pacific, 2013).

supporting disabled people in matters pertaining to healthcare, education and employment. The DSW defines a disabled person as:

> Any person who is unable to obtain for himself/herself, fully or partially, the normal requirements of an individual and/or is unable to participate fully in the community due to shortcomings either physically or mentally and whether it occurred since birth or later in life (Department of Social Welfare, 2009).

It has been argued that the definition used by the DSW is based on the medical approach (Kuno, 2007; Sinnasamy, 2006) which focuses on impairments rather than environmental restrictions (Adnan and Hafiz, 2001; Sinnasamy, 2006). However the Persons with Disabilities Act 2008 (Act 685) or PWDA 2008 defines disabled people differently:

> Persons with disabilities include those with long term physical, mental, intellectual or sensory impairments which in interaction with multiple barriers may hinder their full and effective participation in society (Persons with Disabilities Act 2008, 2008: 8).

The PWDA 2008 definition integrates the medical model and the social model of disability in contrast to the DSW definition which is solely focused on impairment. However, both definitions are used concurrently in the Malaysian practice. In terms of terminology, an individual with impairment is known in Malaysian language as *‘Orang Kurang Upaya’* (OKU) or in English as ‘persons with disabilities’ (PWD) or ‘disabled persons’. Previously, the government used many terminologies to describe disabled people such as ‘handicapped’, ‘less fortunate’, ‘special people’ and ‘less-than-able’ (Wan Arnidawati, 2013). These terminologies carried less favourable messages regarding disabled people and they urged the government to use more positive language to promote a healthier self-image. Following on from that demand, the government introduced the term OKU or PWD to be used in most policies and provisions relating to disabled people.

Even so, disabled people and members of public are in dispute over the current terminology; especially the Malay version of OKU. It is argued that the term OKU literally translated into English means ‘less able person’ (Norazit, 2010: 266). The expression seems to underestimate the ability of disabled people and thus it was suggested that the term should be changed to more appealing words like '*orang kelainan upaya'* or 'differently abled person' (Irfan, 2009; Norazit, 2010). Nevertheless, the government continues to use the existing term of OKU. This thesis however employs the term 'disabled people'.

It is also argued that Malaysia has lack of systematic data on the prevalence and demographic statistics on disability (Department of Development for Persons with Disabilities, 2010; Kuno, 2007). Although the Malaysian Population and Housing Census collected the information on disability, the data on disability prevalence has never been published (Siti Zakiah, 2003). The WHO World Health Survey (from 2002-2004) estimated that the prevalence of disability in Malaysia was 4.5 percent (1.27 million) of the total population (WHO, 2011a) while the Malaysian government estimates that only about one percent of population (283,000) have some form of disability (Sayed Abd Rahman, 1995; Jayasooria et al., 1997).

However in 2013, the number of registered disabled people with the DSW, based on voluntary registration, was 464,967 people (Department of Social Welfare, 2013). This figure exceeds the Malaysian government's official estimated number of 283,000 disabled people based on the one percent rate. This strongly suggests the one percent rate estimated by the government is a massive underestimate and, if the WHO estimate is applied, it appears that only 36.5 percent of disabled people are registered - 63.5 percent of them have still not registered with the DSW. Although the DSW has conducted campaigns to encourage registration among disabled people, the majority of them have not taken the opportunity to do so which may be due to the cultural and social stigma within society (Jayasooria, 2000) and inadequate disability benefits. Also the collective nature of Malaysian society which is 'sociocentric', where family bond is central: the family may take full responsibility for looking after a disabled family member and many of them may not therefore register their disabled child to the state. This situation is exacerbated by a lack of registration awareness. Thus it can be argued that the available data on disability prevalence in Malaysia underestimates the actual numbers of disabled people in the population (Siti Zakiah, 2003) and the majority of them are still underrepresented.

In terms of registration of disabled people, the government appointed the DSW and the MOH as responsible agencies. The DSW classified disabled people into seven categories of impairment for registration purposes: learning disabilities, physical disabilities, hearing disabilities, visual disabilities, mental disabilities, speech disabilities and multiple disabilities. Those who registered with the DSW will be given an OKU card (disability identity card) with a different colour for different categories of impairment (see table 1.1). Learning disabilities (170809) and physical disabilities (153918) are the two largest groups that making up of 69.8 percent of the total number of disabled people registered with the DSW in 2013 (Department of Social welfare, 2013).

Table 1.1 Registrations of Disabled People in 2013

No	Disability Category	Number of Registration	Card Colour
1	Learning disabilities	170809	Yellow
2	Physical disabilities	153918	Green
3	Hearing disabilities	55517	Purple
4	Visual disabilities	42909	Blue
5	Mental disabilities	16998	White
6	Speech disabilities	2725	Brown
7	Multiple	22091	Red
	TOTAL	464967	

(Categories of disability and registration with the DSW as at June, 2013)

1.3.1 History of disability welfare

The development of structured social work with disabled people in Malaysia can be categorized into three overlapping periods as suggested by Jayasooria and Ooi (1994). The first period can be classified as the institutional period (from 1940 to 1960), the second period saw the emergence of self-help organisation (between

1960 and 1980) and the third period saw the development of community based services starting from the early 1980s. The beginning of social work with disabled people in Malaysia can be traced from the initial voluntary work done by Christian missionaries in the early 20th century. The Sisters of the Infant Jesus for example established the Home for Handicapped to cater for abandoned disabled babies in 1911 (Jayasooria and Ooi, 1994) and the Anglican medical mission established St. Nicholas home for the blind in 1926 (Jayasooria and Ooi, 1994; Sinnasamy, 2006). However it is argued that for many years the primary focus of social work services for disabled people in Malaysia was based on the concept of 'charity' or 'caring society' that placed the responsibility for looking after disabled people on the families and communities (Jayasooria, 2000, Kuno, 2007; Wan Arnidawati, 2013).

The first period of disability welfare – institutional care - began after the Second World War when the colonial rulers started to provide state intervention services for disabled people through institutional support (Jayasooria and Ooi, 1994; Sinnasamy, 2006). It was then followed by the establishment of the Department of Social Welfare (DSW) in 1946 (Jayasooria and Ooi, 1994; Sinnasamy, 2006; Kuno, 2007). The primary role of the DSW was 'to care for the crippled, blind and feeble-minded' (Department of Social Welfare, 1946:11 quoted in Jayasooria and Ooi, 1994: 97). In 1953, the Jubilee Home was established to cater for people with 'severe mental disabilities' and children with multiple disabilities (Jayasooria and Ooi, 1994: 97). From the 1950s several charitable and welfare organisations were formed with the encouragement of the government to fulfil the needs of disabled people based on the institutional care framework (Kuno, 2007; Jayasooria and Ooi, 1994). The system of institutional care adopted by the state and the voluntary organisations in the period of 1940 to 1960 led to the segregation of disabled people from the mainstream society (Jayasooria and Ooi, 1994). It is argued that it failed to empower disabled people in 'participation in decision making, policy formulation, resource allocation and service provision' (Jayasooria and Ooi, 1994: 98).

Therefore a deinstitutionalization approach was introduced by the 1960s that marked the second period of disability welfare - the emergence of self-help organisations (Jayasooria and Ooi, 1994). During 1960s and 1970s disabled people’s movements emerged to challenge the traditional approaches that segregated disabled people from mainstream society (Jayasooria and Ooi, 1994). The first disabled people’s organisation was formed by a group of people with visual impairments who established St Nicolas home and later formed the Society of the Blind in 1966 (Jayasooria and Ooi, 1994). The trend for self-help organisations continued with the emergence of the Society of the Orthopedically Handicapped (1976), the Society of Chinese Disabled Persons Malaysia (1977), the KL Society of the Deaf (1987), and the Malaysian Spinal Injury Association (1995) (Jayasooria and Ooi, 1994). Many other disabled people’s organisations have been formed in Malaysia since then.

However, the programs run by the non-governmental organisations (NGOs) for disabled people may not be as well monitored as governments in developing countries like Malaysia often have little control over their voluntary organisations (Pressman and Heah, 1988 quoted in Barnartt 1992: 56). Thus the self-help organisations in Malaysia do not have direct accountability to the government as they emerged as independent entities. Nevertheless at the same time, in 1970s, the discourse of rehabilitation came into practice in Malaysia to provide care and rehabilitation to integrate disabled people into society. It was supported by the establishment of a School of Physiotherapy in 1974 (Kuno, 2007). Since then the trend for self-help organisations and rehabilitation approaches has continued to play an important part in the advancement of disabled people in Malaysia (Armstrong, 1993).

The third period of disability welfare - development of community based services - began in the early 1980s (Jayasooria and Ooi, 1994). This approach was based on advocacy principles and ‘saw a further development of joint action among organised and informal groups of disabled persons’ (Jayasooria and Ooi, 1994: 98). Disabled people’s movements collaborated among themselves to express their view and take joint action on behalf of disabled people. As a result, the Malaysian Confederation of the Disabled (MCD) was established in 1985 to act as a national body representing several disabled people’s organisations. The MCD seeks to form a more direct link with the government through memorandums and accessible forums on equal opportunities for disabled people that influence the government policies (Wan Arnidawati, 2013).

Parents of disabled people also began to join with disabled people's organisations to play active roles in their demands for equal and full participation in society (Jayasooria and Ooi, 1994). The public and media also gave support to this trend and on one important occasion covered by the media in 1994 the disabled people's movements, together with the public, organised a public demonstration to demand equal access to the new light rail transport system. Consequently, the government responded to their demand and agreed to build a fully accessible light rail system (Kuno, 2007). Since then, the disabled people's movements have turned their actions into a more active and effective role striving for the wellbeing of disabled community as a whole.

1.3.2 Development of disability provisions, policies and legislation

The development of disability welfare in Malaysia has undeniably undergone significant improvements and transformations since the period of colonialism. Disabled people are now becoming more actively involved in the formulation of support and policies provided for them. It is argued that although disability prevalence is higher in developing countries, only in a few of them has disability policy been formulated for disabled people (Barnartt, 1992). This section will explore the fundamental aspects of social provisions, policies and legislations for disabled people in Malaysia through the government's initiatives and collaborations with disabled people's organisations, the local and international agencies.

In the past twenty years, the government has introduced disability provision relating to education, training, employment and welfare for disabled people (Wan Arnidawati, 2013). As discussed, the primary welfare provider is the DSW under the MWFCD but other ministries are also involved in matters pertaining to disabled people. Currently, there are four main social policies relevant to disabled people in Malaysia: National Welfare Policy (1990), National Social Policy (2003), National Policy for Persons with Disabilities (2007) and National Plan of Action for Persons with Disabilities (2007-2012) (Department of Development for Persons with Disabilities, 2010). The following sections will discuss various supports given by the government to disabled people.

For example in terms of healthcare, the government provides significant supports for disabled people (Kamarulzaman, 2007). Every disabled person registered with the DSW is entitled to receive medical benefits such as rehabilitation and further medical treatment, exemption from medical fees at all government hospitals, and financial support regarding medical treatment, rehabilitation or prosthesis aids (Department of Development for Persons with Disabilities, 2010).

In terms of education, disabled students are provided with several educational programmes. The Ministry of Education (MOE) is responsible for the formal education of disabled students under four main categories: ‘visually impaired’, ‘hearing impaired’, ‘orthopedically impaired’ and ‘mentally retarded’, or those with ‘mild learning difficulties’ (Kamariah, 2003 quoted in Jayasooria, 2000: 69). The MOE provides two approaches to education for disabled students. The first is ‘special education’ which offers education in special schools for students with hearing and visual impairments. The second is ‘integrated education’ in which disabled students attend mainstream schools, but study in separate classes from other students (Kuno, 2007). The special education curriculum for students with learning difficulties in the public schools began to be introduced in this form in 1988 (Yeo, 2007). Since then, the enrolment of students with learning difficulties in the ‘integrated education’ has increased dramatically in primary and secondary schools from 1996 to 2008 (Special Education Division, 2008). Students who join a special education class in public schools receive RM150[5] (£27.47) per month and those in higher education are given RM300 (£54.95) per month as a financial incentive (Department of Development for Persons with Disabilities, 2010).

In addition to the formal education system for disabled students, the government also introduced a Community-Based Rehabilitation (CBR) program, which is administered by the DSW. The CBR was first implemented in 1983 with collaboration from the World Health Organisation (WHO) (Kuno, 2007; Jayasooria, 2000). The CBR in Malaysia was implemented based on the concepts of CBR as originated by the WHO (Sayed Abd Rahman, 1995). It aims to provide

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[5] RM is the currency symbol of the Malaysian Ringgit. 1 Pound Sterling (£) is equal to RM5.46 as indicated by the Central Bank of Malaysia based on ‘Ringgit Foreign Exchange Rates’ on 16 July 2014 (Central Bank of Malaysia, 2014).

educative and rehabilitative intervention for disabled people within the community, via assistance from family members and the local community (Kuno, 2007). In the initial stage of the development of the CBR in Malaysia, it was initiated by the district officer. Later a CBR committee was formed, mostly by parents of disabled children in the community. By the year 2000, around 243 CBR centres were formed and 5572 disabled people were participating in the programme throughout the country (Department of Statistics Malaysia, 2010). Also the government provides 11 institutes for rehabilitation and care for people with different categories of impairment: seven rehabilitation institutes for people with learning difficulties, two workshops for those who cannot secure employment in the community, one vocational and rehabilitation institute for those with physical impairment and one rehabilitation care home for patients with mental health problems (Department of Development for Persons with Disabilities, 2010).

The government also implemented several employment policies for disabled people. The Ministry of Human Resource (MOHR) for instance has consistently conducted annual campaigns to promote the employment of disabled employees in the public sector and this has led to the implementation of a code of practice for the employment of disabled people in 2001 (Kuno, 2007). Consequently, in 2008, a one percent quota system for disabled employees in the public sector was implemented (Department of Social Welfare, 2011; Kuno, 2007). It secured employment opportunities for disabled people in the public sector and from its inception up until June 2012 about 2,415 (0.12 percent) disabled workers have been employed in various public agencies. Equally the government has given incentives for the private sector to employ disabled workers: companies who hire disabled people can claim ‘double tax deductions on all salary payments, expenses incurred in training and adaptations made to the workplace’ (Wan Arnidawati, 2013: 24). However, only 7467 disabled workers were employed in the private sector up until the year 2008 (Ministry of Women, Family and Community Development, 2009).

The DSW also implemented some initiatives to encourage employment for disabled people. For example, the DSW collaborates with an international agency - the Japan International Cooperation Agency (JICA) and introduced the ‘Job

Coach' program for disabled people which has been running since 2006 (Department of Social Welfare, 2011). It aims to assist disabled workers and employers in forming a mutual understanding in terms of the nature of work, essential facilities or training required by disabled workers, as well as promoting a conducive and productive working environment for disabled people. The Registration System for Persons with Disabilities (SPOKU) has also been implemented in collaboration with the MOHR and up to December 2008, around 10332 disabled workers were placed in the private sector (Department of Social Welfare, 2011). The DSW also gives a Disabled Employee Allowance (*Elaun Pekerja Cacat* - EPC) of RM300 (£54.95) per month for those earning an income below RM1200 (£219.78) to encourage them to remain in employment and be self-supporting; while those who are unable to undertake employment are given RM150 (£27.47) per month (Department of Social Welfare, 2009). Despite various supports and incentives provided by the government, the employment rate for disabled people is still below one percent in both the public and private sectors (Labour Department Malaysia, 2005).

Additionally, in terms of transportation, the government offers 25-50 percent discount for public transport fares, and those using a nationally produced car are exempted from road tax and receive a 50 percent reduction in excise duty for running a disability vehicle. The government also provide support with housing allocation where the Kuala Lumpur City Hall (DBKL) offers a discounted rent for local council flats and the Syarikat Perumahan Negara Berhad (SPNB) gives a 20 percent discount for low-income disabled people to buy low-cost accommodation. The national telecommunication provider, Telekom Malaysia also provides free line rental for a home telephone (Department of Development for Persons with Disabilities, 2010).

Disabled people also had the opportunity to actively engage in the formulation of government policies that brought significant changes, albeit incomplete, (Jayasooria, 1999) over the past 20 years (Wan Arnidawati, 2013). For example the Uniform Building By-Laws of 1984 (UBL 1984) was amended in 1990; it requires all public buildings to provide necessary facilities for disabled people, and the Malaysian Standard Code of Practice for disabled people's access to public buildings was released two years later (United Nations Economic and

Social Commission for Asia and the Pacific [UNESCAP], 2003). The disabled people's organisations were also involved in convincing the government to sign the Proclamation on Full Participation and Equality of Persons with Disabilities in the Asia and Pacific on 16 May 1994 (Tiun et al., 2011a). The government's commitment was then articulated in the formulation of 'Vision 2020'[6] to establish a 'caring society' as part of the nation's ambition to become a fully developed country by year 2020 (Kuno, 2007; Jayasooria, 2000; Department of Social Welfare, 2009). Then in October 2002 the government adopted the Biwako Millenium Framework (BMF) to engage with an inclusive, barrier-free, and rights-based society for disabled people (Economic Planning Unit, 2007).

Later, the National Policy on Persons with Disabilities was introduced in 2007, leading to the enactment of the Persons with Disabilities Act 2008 (PWDA 2008). The Act was endorsed by the Malaysian Parliament on 24 December 2007 and implemented on 7 July 2008. It was the first legislation to afford fundamental recognition of the rights of disabled people in Malaysia (Department of Development for Persons with Disabilities, 2010). The PWDA 2008 is said to acknowledge disabled people's rights and to change the disability concept from a welfare-based to a rights-based approach (Department of Social Welfare, 2009). The underlying principles of this act are to provide equal opportunities for disabled people and to promote full participation of disabled people in society; focusing on the registration, protection, rehabilitation, development and wellbeing of disabled people (Persons with Disabilities Act, 2008).

Following on from that, the year 2008 marked a significant development in disability welfare when the National Plan of Action for Persons with Disabilities (2008-2012) was announced and the Disabled Unit in the DSW was upgraded to the Department of Development for Persons with Disabilities (*Jabatan Pembangunan Orang Kurang Upaya* [JPOKU]) (Department of Social Welfare,

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[6] Vision 2020 is a Malaysian ideal plan introduced by the former Prime Minister of Malaysia, Mahathir Mohamad in the Sixth Malaysia Plan in 1991. It calls for the nation to achieve a self-sufficient industrialized and fully developed nation by the year 2020: it encompasses all aspects of life, from economic prosperity, social wellbeing, and educational world class, to political stability and psychological balance. Its declaration was then followed by the rapid growth of an industrial based economy as a strategy to eradicate poverty by the creation of employment opportunities, fostering economic commercialism for Bumiputera, encouraging privatization, and human resource development. Since then, Malaysia has experienced prosperous economic development and has been one of the most successful countries in Asia (Economic Planning Unit, 2011; Nirwan, 2004).

2009). In the same year Malaysia also became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); this was ratified two years later on the 19 July 2010 (Department of Social Welfare, 2011).

This perhaps indicates a stronger commitment from the government to improving the wellbeing of disabled people (Wan Arnidawati, 2013). However a systematic integration between the state's agencies was still lacking in dealing with disability issues. Disability welfare is seen as heavily dependent on the Ministry of Women, Family and Community Development and its main welfare agency – the DSW. In order to have inclusive disability welfare the government should ensure that other agencies, such as the Ministry of Urban Wellbeing, Housing and Local Government, Ministry of Education, Ministry of Human Resource, Ministry of Transport and Ministry of Health, work together in matters pertaining to disabled people. This is important to ensure that accessible housing, education, employment, transport, healthcare and recreation for disabled people can be achieved. Therefore despite the increasing commitment from the government to cater the rights of disabled people in the country, it still has a long way to go.

1.3.3 Major challenges for disabled people

Although the Malaysian government has developed significant disability provisions, policies and legislations, disabled people still encounter major barriers in many aspects of their lives. This section briefly describes the major challenges experienced by disabled people in terms of healthcare, education and training, employment, transportation and physical environment. It will then discuss the pertinent issues involved behind these underlying disability struggles.

The first major challenge that underpins disabled people's lives is that of healthcare. Whilst the government provides significant medical assistance for disabled people as described, issues related to the early assessment of impairment and accessibility of medical rehabilitation services are still paramount. Amar-Singh (2008) argues that there are no uniform medical tests for diagnosing many childhood disabilities in Malaysia and the majority of services adopted their models from industrialised countries, which may not applicable for the vast needs of local children. Furthermore, he argues that services for disabled children are fragmented, hospital-based, and inadequate; while parents encounter difficulties from the service providers (Amar-Singh, 2008). Also Kuno (2007) argues that accessibility to medical rehabilitation services is limited; especially in district or village areas. In Malaysian practice rehabilitation specialists basically work in the hospitals at a national level, and are principally located in the populous areas, whilst most of the rehabilitation therapists are confined to the state level, with the majority of them at hospitals in urban areas. Therefore, rehabilitation services are not available at most of the district or the rural hospitals. As a result, it is difficult to provide adequate services for disabled people in rural areas.

The second challenge for disabled people is in terms of education and training. Although the government provides formal education programmes for disabled students, several issues have become major concerns. It was argued that children with severe physical impairment were often excluded from school because the responsibility for education of physically disabled students is not the remit of the MOE, but is within the scope of the DSW (Kuno, 2007). Also disabled children in rural areas, regardless of the type of disability, have fewer opportunities to attend formal education (Kuno, 2007). As a result, students with severe physical impairment and disabled children from rural areas often encounter barriers in terms of accessibility to, and the facilities provided by, the mainstream schools (Ong et al., 2002). A study conducted in East Coast of Peninsular Malaysia found that the majority of mainstream schools were inaccessible for wheelchair users and students with mobility impairments. Laboratories and libraries were usually located on upper floors and thus prevented students with mobility impairment from accessing the facilities (Kamarulzaman, 2007). Students in tertiary education also face environmental and attitudinal barriers at higher learning institutions. It was found that disabled students (with different categories of impairments) in a public university in Malaysia encountered significant environmental barriers in terms of inaccessible physical infrastructures on campus, lack of sign language interpreters for hearing disabled students, lack of accessible computers for visually disabled students, and inaccessible transportation services. Additionally there were also attitudinal barriers, such as issues of bureaucracy and lack of empathy from members of the institution (Hasnah et al., 2009).

The third challenge that undermines disabled people's wellbeing is the difficulty of gaining employment. Despite various employment policies and incentives provided by the government to encourage employment for disabled workers, findings demonstrate that employment rates among disabled people are low (Ramakrishnan, 2007; Mubarak, 2006; Faridah, 2003; Jayasooria, 1997) and there are no official statistics on the actual numbers of disabled people in employment (The Equal Rights Trust, 2012). The phenomenon of unemployment among disabled people in Malaysia can be explained by two main factors. First, disabled workers have to face attitudinal barriers from employers (Jayasooria, 1997; Ramakrishnan, 2007; Faridah, 2003). It has been argued that Malaysian organisations have limited experience in managing disability issues and therefore have negative attitudes towards disabled employees (Tiun et al., 2011b). Lack of exposure to disability related issues have made employers reluctant to provide employment opportunities due to their lack of awareness and knowledge on the issue of accommodation, supervision and training costs for disabled workers (Ramakrishnan, 2007). Second, environmental barriers at workplaces have become a major issue for disabled employees in Malaysia. Jayasooria (1997) argues that although industrialization in Malaysia has improved facilities provided for the public, many disabled people are still excluded from them due to environmental constraints in getting to these amenities; especially in getting to the workplace and within the workplace itself.

The fourth major challenge for disabled people in Malaysia, and one that has been debated for many years, is in terms of transportation and physical environment. Although the government has implemented the Uniform Building By-Laws (amended in 1992) and PWDA 2008 underlining the right for equal access to physical environment and public transport, in reality, many disabled people have expressed their disappointment over the barriers they encountered when using public transport and getting access to public buildings. It has been argued that accessible public transport for disabled people in many parts of the country is not adequate (Kamarulzaman, 2007). Disabled persons who use mobility aids, such as wheelchairs or crutches for example, have to depend on taxis which are more expensive than other types of public transport. In some cases taxi drivers have refused to accommodate wheelchair users (Kamarulzaman, 2007). As a result many disabled people are confined to their homes because of inaccessible public transport (Jayasooria, 1997). Also, included among the common problems experienced by disabled people at public places are: there are many steps and steep drops for wheelchair users, ramps are not properly constructed, pavements with uncovered drains, control panels in elevators which are unsuitable for visually disabled or wheelchair users, narrow or too heavy doors, poorly designed guide tiles for visually disabled people, inappropriate toilet design for disabled people and improper parking space for disabled people (Kamarulzaman, 2007; Jayasooria, 1997; Tiun 2010).

In regard to the many challenges discussed above, it is clear that the disability policies and legislation implemented by the government have not achieved their objectives; especially those of the PWDA 2008. Many parties, especially disabled persons and disabled people's movements, have raised concerns about the effectiveness of the PWDA 2008 in relation to its enforcement. The Malaysian Bar Council Law Reform and Special Areas Committee, for example, addressed key issues related to the Act. They argued that the Act has no element of penalty at all for those who fail to fulfil the obligations under the act, including the Federal Government (Malaysian Bar Council, 2009). Although the DSW claims the Act was created using the principle of a rights-based rather than a welfare-based model, the current provisions in the Federal Constitution do not allow this to happen. For instance, under Article 8 of the Federal Constitution, a disabled person might claim his or her right as in Clause One it affirms that 'all persons are equal before the law and entitled to the equal protection of the law' (Federal Constitution, 2009:14). However in Article 8(2) of the Federal Constitution, it falls short of prohibiting discrimination on the ground of disability as it states 'there shall be no discrimination against citizens on the ground only of religion, race, descent, and place of birth or gender' (Federal Constitution, 2009: 14). Therefore, no other grounds except those mentioned in the constitution qualify as discrimination. The absence of sanctions for non-compliance in the PWDA 2008 makes it an administrative document only and ineffective for implementation (Jayasooria, 2000; Malaysian Bar Council, 2009).

Another issue is the question of real commitment to implement the Act. Effective implementation is difficult due to the absence of national data on disability prevalence. Planning proper training of the welfare officers, teachers, police officers, and other related parties is problematic as there are no statistics for the total population of disabled people (Malaysian Bar Council, 2009). It is also clear that the implementation of social policies and legislation for disabled people relies on political pronouncements and incentives from the government rather than on social legislation and statutory punishment (Jayasooria, 2000). This is mainly due to the previous concept of welfare-based or 'caring society' practised by the Malaysian government in managing the issue of disabled people (Kuno, 2007). The social welfare of disabled people is based on the goodwill of the community to conform to the appeal and incentives made by the government and not based on the question of rights (Jayasooria, 2000). For many years, the efforts to foster the social participation and independence of disabled people in Malaysia were perceived within a welfare context rather than within a human rights context (Kuno, 2007) and only recently the concept of right-based was introduced.

Therefore the implementation of social policies and legislation to cater for the rights and needs of disabled people will not reach its objective unless the approach is firmly changed from a welfare-based one to a rights-based one. Also it is vital to note that this poor implementation of disability policies may intersect with other policy problems in Malaysia such as poverty, poor public transport system, poor housing, and inaccessible education and healthcare in rural areas. Thus the government's commitment to transform disability welfare from the welfare-based to the rights-based approach should be put into real practice rather than exist only in the documentation. In addition it should incorporate other policy problems in Malaysia.

1.4 (Disabled) women in Malaysia

In the post-independence era Malaysian women have gradually enjoyed equal opportunities in their access to basic social needs and services. They have gained significant life improvements and play important roles within the family, organisation and societal level in contributing to the national agenda, together with men (Ministry of Women, Family and Community Development, 2007). As a member of the United Nation Human Rights Council (UNHRC) Malaysia has signed the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) in 1980, and acceded to the Convention in 1995 with some reservations[7] (UN Women Regional Office for Asia and the Pacific, 2013). In January 2001, the Ministry of Women's Affairs was established and later it was expanded and renamed as the Ministry of Women and Family Development in February 2001. In March 2004, the roles and functions of the Ministry were further broadened and subsequently the Ministry was restructured and renamed as the Ministry of Women, Family and Community Development (MWFCD) which is also responsible for looking after disabled people; as discussed earlier (Ministry of Women Family and Community Development, 2013).

Whilst the importance of women is recognised at the local and international level, gender disparity is still prevalent in Malaysia and research on disabled women is very limited. In the previous section some of the issues and challenges that undermined the lives of disabled people in Malaysia were discussed: however based on the available, albeit inadequate research, little is known of how Malaysian disabled women experience their lives. This section therefore will explore how (disabled) women in Malaysia and elsewhere experience their lives in terms of gender norms, access to healthcare, education and training, economic participation, violence against them and their participation in politics and public life. Some examples from the Global South and the Global North will also be given to observe how disabled women experience their lives globally: including particular countries such as India and China, as well as Muslim countries, to draw some parallels with the multiple ethnic groups and religions in Malaysia.

1.4.1 Gender norms

Disability is argued to have some relation to gender (Morris, 1992; Thomas, 1999) and culture (Shakespeare, 1994; Ingstad and Whyte, 1995; Riddell and Watson,

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[7] Malaysia ratified the CEDAW with some reservations on Article 5 (a), 7 (b), article 9, paragraph 2, article 16.1 (a) and paragraph 2. 'The Government of Malaysia declares that Malaysia's accession is subject to the understanding that the provisions of the Convention do not conflict with the provisions of the Islamic Sharia' law and the Federal Constitution of Malaysia' (UN Women, 2009).

2003). Women's identities are acquired through their reference to gender norms that make up their social worlds (Thomas, 1999). Gender is not the biological difference between male and female, instead it is the socio-cultural distinction between men and women (Oakley, 1972). Gender norms are therefore 'socially-constructed ideals, scripts, expectations for how to be a woman or a man; [...] they determine who does what, to whom, when, and how' (Wallace and Wilchins, 2013: 1). Gender norms play significant roles on how women are perceived within a society and thus disabled women may be perceived differently across cultures. This section will explore how cultural conceptions of the traditional gender roles, and societal stereotypes of what constitutes 'femininity', may influence disabled women's lives.

In any given society, especially in traditional societies, men and women are expected to perform different gender roles (Thomas and Thomas, 1998). Gender roles are determined by historical, ideological, ethnic, religious, economic and cultural factors (Moser, 1993). Malaysia for example still maintains strong traditional gender roles within its society. Despite the increased opportunity for women to play significant roles outside the family, women are still bound to the traditional socio-cultural values of Malaysian society. Traditionally, women in Malaysia are associated with the primary roles of engaging with the family, marriage and children (Yun, 1984). The traditional role of women expects them to take the responsibility for all domestic chores and to fulfil the basic functions of a wife and mother such as cooking, cleaning and caring for the household (NGO Shadow Report Group, 2005; Aminah, 1998). Moreover, women in the family-building stage tend to not work, as the primary focus is given to the family (Chattopadhyay, 1997).

Disability can therefore have a profound impact on disabled women's ability to carry out traditionally expected gender roles because disabled women are stereotyped as 'incomplete' (Mehrotra, 2008: 40) and people may perceive them as unqualified to perform such roles. Disabled women in rural areas of South Sulawesi Indonesia for example were viewed as incapable of carrying out domestic activities within the family (Schuller et al., 2010). Disabled women in Arab countries are also subjected to gender-based prejudice and many disabled women suffer from 'double discrimination' due to prejudiced perceptions and discrimination against them (Nagata, 2003). Some studies have also suggested that disabled women may be less likely to get married than disabled men and non-disabled women (Nagata, 2003; Rao, 2010) because people may have an automatic assumption that their disability will prevent them from fulfilling the traditional gender roles within a family (Begum, 1992). As Thomas and Thomas argue:

> Many people carry the misconception that because of her physical disability, a woman may not be competent in any sphere, and that a physically disabled woman is also unable to think, learn or work (Thomas and Thomas, 1998: 61).

It has also been highlighted that the media rarely portray disabled women in traditional roles as wives and mothers (Fine and Asch, 1988 cited in Barnes and Mercer, 2010: 194). Although many feminists do not support this gender role stereotyping, disabled women want the media to display a variety of images of disabled women, including those where women are depicted in their domestic roles as wives and mothers (Barnes and Mercer, 2010). This stems from a need to counter the societal misconception of them. For instance in rural areas of China, the family will strongly oppose the decision if a non-disabled family member intends to marry a disabled woman (Zhang, 2007). Likewise, disabled women in India are usually married to disabled men, widowers, men who are economically lower than the women's family, or may even marry men who cannot find a spouse for other reasons such as illiteracy, low income or caste endogamy (Mehrotra, 2008). In Muslim countries, such as in the Arab region, disabled women are also discriminated against in love and marriage. For example, the majority of disabled women in Jordan have often been found to be unmarried and some parents over-protect their disabled daughters from marriage (Nagata, 2003). South Asian disabled daughters living in Britain also had less chance of being married than disabled men due to their parents' attitudes as they do not view the marriage prospects of disabled daughters positively (Hussain, 2005).

In addition to manifold barriers to relationships and marriage associated with the strong traditional gender roles within society, disabled women also experience barriers to motherhood. For example, research conducted in Lusaka, Zambia found that disabled women encountered various social, attitudinal and physical barriers in accessing safe motherhood and reproductive healthcare (Smith et al., 2004). Moreover many disabled women across societies also experience barriers to motherhood (Lonsdale, 1990; Thomas, 1999). Some physicians for instance do not have adequate knowledge of how to handle pregnancy among disabled women and this can lead to inadequate treatment to disabled mothers. Also, McFarlane (2004) in her PhD research on disabled women and socio-spatial 'barriers' to motherhood in Glasgow and Edinburgh found that from a historical perspective disabled women have been stereotyped as not capable of undertaking reproductive or mothering roles. For which Frohmader and Meekosha argue:

> Women with disabilities have traditionally been discouraged from or denied the opportunity of bearing and raising children. They are perceived as being asexual/overly sexual, dependent, recipients of care rather than caregivers, and generally incapable of looking after children (Frohmader and Meekosha, 2012: 296)

In addition, disabled women are also subjected to societal stereotypes of what constitutes 'femininity'. For example physical appearance has something to do with the cultural norms of how society determines the ideal concept of physical image. Disabled women may be most 'disadvantaged' in the cultural conception of what constitutes an acceptable physical appearance within society. Lonsdale argues:

> Physical appearance has long been recognised as something which has particular relevance to women. Women in Western society are required to conform to an image which is based on certain sexual, physical and behavioural stereotypes (which also often imply certain cultural and material lifestyles) (Lonsdale, 1990: 3).

The societal conception of a woman's stereotyped image may have negative consequences for women with physical impairments who may not conform to the physical attributes traditionally embedded within society. Morris (1989) for instance analysed disabled women's experience of paralysis and found that their feelings about their physical appearance were altered in societies which placed great emphasis on the 'beauty' of women's bodies: 'The myth of the beautiful body that society and the maker has created, define the impaired female body as unfeminine and unacceptable' (Ghai, 2009: 288). Consequently, disabled women with physical impairments may be subjected to psycho-emotional consequences and identity conflicts.

In the Malaysian context for instance, the mass media reinforces a stereotypical image of women as young, slim and fair (All Women's Action Society (AWAM), 2003). Many advertisements also used beautiful women to portray Malaysian women. Moreover, women on television are portrayed as weak or dependent on male characters so the locally produced women's programmes reinforced the stereotypical and traditional role of women as dependent on men (Azman and Juliana, 2005; Azman, 2006). At the same time, images of disabled women have rarely been represented on local screens. Therefore, the physical appearance of disabled women in the mass media is almost invisible and as such Malaysian society may not be aware of how disabled women look, tending to have a universal image of women as beautiful, healthy and able-bodied. In conclusion, the gender norms which are strongly embedded within society may influence disabled women's lives at the personal, familial and societal level.

1.4.2 Access to healthcare

Disabled women are not only subjected to the strong traditional gender roles and stereotypes within society but they also have less access to healthcare and rehabilitation services (Thomas and Thomas, 1998; Nosek and Simmons, 2007; The World Bank Group, 2009). This is more profound in developing countries like Malaysia with a diverse geographical population. Although the accessibility of healthcare to the general population is relatively adequate, rural populations, especially in the largest states like Sarawak, Sabah and Pahang, have limited access to the local health facilities (NGO Shadow Report Group, 2005). Hospitals or local clinics are usually located in highly populous areas, and as such, people who are living far from the heart of medical facilities may have limited access to proper medical treatment and information; especially those with mobility impairments as discussed in 1.3.3. The MWFCD in its Report to the United Nations Committee on CEDAW (First and Second Report) in 2004 reported,

> indirect and qualitative evidence to suggest that some groups of women (e.g. disabled/ migrant/ aboriginal or indigenous women) and those who are living or working in estates and plantations are marginalised in

> terms of access to health services and facilities (NGO Shadow Report Group, 2005: 74).

Moreover it is argued that the government does not have gender disaggregated data and analysis on healthcare issues; although women are more likely to develop impairment at a later age because women have a higher life expectancy than men in Malaysia (Sidiah, 2008; Noran et al., 2010; Department of Statistics Malaysia, 2011). The NGO Shadow Report Group (2005) argues that there is a critical need to have gender disaggregated data and analysis for the Malaysian population. The health data collected for the country has not been subjected to gender analysis. Gender analysis in the population's health is important in identifying the prevalence of which common diseases are significant for males and females, for intervention and treatment planning at the national level. For example, the incidence of hypertension, psychiatric morbidity and cancers (all sites) were found to be more common among females than males in the National Health and Morbidity Survey II (Ministry of Health, 1997). Therefore, Malaysian women may be subjected to greater risk of acquiring disability at later age without an appropriate intervention and treatment plan at the national level due to the absence of gender disaggregated data and analysis.

In addition, (disabled) women in Malaysia may experience socio-cultural barriers to proper healthcare treatment and rehabilitation. Some women may be unable to leave the house without their husband's permission, lack alternative child care arrangements, or lack education (NGO Shadow Report Group, 2005). Likewise, many women in a traditional society such as India, especially those who live in a village, do not go out of their houses to seek healthcare assistance if the care-provider is a male (Thomas and Thomas, 1998). Thus, the cultural attitudes towards gender and lack of women practicing in rehabilitation professions may dissuade disabled women from receiving adequate assistive devices and treatments (Thomas and Thomas, 1997; The World Bank Group, 2009).

1.4.3 Education and training

Another fundamental issue that may influence the wellbeing of disabled women in Malaysia is that of education and training. As discussed in 1.3.3, disabled people, especially those with physical impairments, still face significant barriers in gaining access to education despite the government providing formal educational programmes for disabled students. The main issues are in terms of infrastructure and the accessibility of schools. The government's report indicates that 82.9 percent of primary schools and 58.5 percent of secondary schools are located in rural areas throughout the country (NGO Shadow Report Group, 2005). Many schools in rural areas in the state of Sabah were reported to have poor infrastructure and facilities, as well as a lack of teachers.

Moreover many secondary schools are situated far from students' residence; they are concentrated in urban areas and require students to leave home for schooling. This may hinder students from poor families from gaining proper education due to transportation constraints, especially for those students with mobility impairment. For example many disabled children in Malaysia, especially those in rural areas and those who have mobility impairments, are unable to attend schools due to environmental barriers such as inaccessible school buildings and transportation problems (Kuno, 2007; Ong et al., 2002; NGO Shadow Report Group, 2005). Students in higher learning institutions also face environmental and attitudinal barriers in their universities as discussed earlier (Hasnah et al., 2009).

Barriers to education for disabled young women are also common in other countries such as Thailand. Ito (2010) found that young disabled girls with hearing impairments and intellectual disabilities are subjected to inadequate education opportunities and, as such, are easily being exploited. Disabled women in the rural areas of South Sulawesi Indonesia have also been stigmatised, resulting in them receiving minimal education or training (Schuller et al., 2010). In India, disabled women are also subjected to unequal opportunities for proper education. For instance in the Raichur district of the Karnataka State of India, the literacy rate of disabled women was only 7 percent, as compared to the general literacy rate of the state which was reported to be about 46 percent. These examples therefore clearly show that disabled women in many countries have unequal opportunities for education (Rao, 2010).

In comparison, the literacy rate in the Arab regions also indicates similar trends as for example,

> […] in Syria, only 20 percent of women with disabilities were literate, compared to 66 percent of the total female population who are literate and 40 percent for men with disabilities (who are literate). In Bahrain, only 12 percent of women with disabilities were literate, in contrast with 59 percent of the total population of Bahraini women, 79 percent of the total population of Bahraini men, and 36 percent of Bahraini men with disabilities. Literacy among women with disabilities was far lower than that of men with disabilities (Nagata, 2003: 11).

Thus, a comparable pattern of disabled women's opportunities for education can be observed across countries, including Muslim countries.

Additionally the strong traditional gender stereotyping and perceptions which exist within Malaysian society may restrict the equal opportunity for the education and training of female (disabled) students. For example many girls are inclined to avoid subjects outside their traditional gender stereotypes; sciences, technology and engineering, despite the fact that these may lead to a higher-paid job (Aminah, 1998). In service oriented courses, women are associated with hotel and catering, tailoring and commerce training, whereas non-formal education providers are inclined to conduct programmes that are related to women's domestic roles, like food processing, tailoring and handicrafts, as opposed to productive roles (Aminah, 1998). Gender disparity can also be seen in the number of women holding top-level positions within the education system, as reported by the government (NGO Shadow Report Group, 2005). Whilst the majority of teachers in schools are women, fewer numbers of them were promoted to decision-making positions throughout their career path. It thus suggests that the gender gap in education is still too wide and this may have profound impact on female (disabled) students.

1.4.4 Economic participation

Many disabled people face significant environmental and attitudinal barriers in their employment experience as discussed in 1.3.3. Research into the career experience of disabled women in Malaysia found that disabled women encountered significant discrimination in terms of job appointments, career appraisals, physical barriers at the workplace and work related places, a lack of support from leaders and a lack of understanding about disability issues as demonstrated by employers (Faridah, 2003). Other countries also found that disabled women experienced some forms of discrimination in employment. Dhungana (2006) for instance found that gender bias exists in terms of training and employment opportunities in Nepal, whilst Cameroonian disabled women experienced ‘three-fold’ discrimination in terms of gender, perceived inability, and low socio-economic status (Kiani, 2009). Disabled women in China are also found to have a lower income than disabled men as many women stay at home, especially in rural areas (Zhang, 2007). Women in the Arab countries are also reported as having limited labour force participation. In the national census of Kuwait, only two percent of disabled women were in the labour force as compared to about 10 percent of disabled men (Nagata, 2003). Accordingly, disabled women across countries may experience gender disparity when compared to disabled men.

Whilst the Malaysian government has introduced various employment policies and incentives to encourage employment for disabled people, findings demonstrate that employment rates among them are still too low (Ramakrishnan, 2007; Mubarak, 2006; Faridah, 2003; Jayasooria, 1997). Many disabled people from various categories of impairment are unemployed, as compared to the larger population, and this effect may be more profound for disabled women. Malaysian disabled women may not only encounter the environmental and attitudinal barriers in relation to their disability but also the socio-cultural constraints as discussed in 1.4.1. For example until the 1960s Malaysian society had a commonly held belief that women were ideally suited as housewives and, when educated, they should work as teachers, nurses, or in similar ‘feminine’ occupations (Koshal et al., 1998). Also, the primary role of women is assumed to be that of home-maker and the women’s status is perceived to be lower than men in all three main ethnic groups - Malay, Chinese and Indian: this despite the increasing numbers of women now entering the workforce (Noraini, 1999). Therefore, disabled women may not be perceived as equal to disabled men in securing employment because the society values men as breadwinners, rather than women.

Nevertheless, women's employment has undergone structural changes in the Malaysian economy. The shift from being an agricultural economy to being one based on industry and services has rapidly increased women's employment in the wholesale, retail trade, hotel, restaurant sector and also the financial segment (Ministry of Women, Family and Community Development, 2007). It has marked a steady incremental increase of women's participation in the labour force which witnessed an increase of about 44.7 percent in 1995 to 46.1 percent in 2010 (Department of Statistics Malaysia, 2011). Although current trends show significant improvement in the participation of women at work, the rate is far lower than men as evidenced by the fact that 70.5 percent women did not participate in the labour force compared to only 29.5 percent of men being outside the labour force in 2011 (Department of Statistics Malaysia, 2011). Disabled women face even greater risk of unemployment. Thus, women in general are still behind men regarding participation at the workforce.

Although there was a slight increase in women's participation in the labour force as more women became likely to work, the decision to work or not may depend on the burden of work, childcare, and household duties (Ministry of Women, Family and Community Development, 2007). It is noted that women's enrolment in the labour force is associated with the attitude of the family towards women (Aminah, 1998). The changing attitudes of parents and husbands encouraging higher educational attainment of women could be a factor affecting women's participation at work (Fatimah, 1993). The non-traditional attitude towards gender roles by husbands also has important implications for rural women's economic participation as women would be less burdened with household chores (Aminah and Narimah, 1992). A positive attitude of a husband and wife on equality regarding domestic work could allow women to participate in the labour force more effectively and this may also affect married disabled women.

In addition, previous studies established that women are generally represented within the subordinate management and lower paying positions (Yousof, 1995; Tan, 1991). Similarly, in business organisations and private sectors, women were found not to be getting equal opportunities for promotion after recruitment. Female managers also received resistance from both male and female subordinates with respect to their career advancement (Koshal et al., 1998). As indicated in the Global Gender Gap Index 2012, Malaysia ranked very low - 98 out of 135 countries - for the gap between women and men on economic participation and opportunity (World Economic Forum, 2012). Obviously, career advancement for women still lags behind that of men, and is restricted to lower positions as opposed to attainment of higher-level or decision-making positions.

Another common dilemma of working women in the private sector is the wage differences relative to their male colleagues. The policy of unequal pay between men and women employed has been well rooted since the colonial era. Later, when Malaysia obtained independence from the British in 1957:

> the policy of unequal pay between men and women was continued by the government until the struggles by women's groups and trade unions succeeded in achieving equality in pay for all government employees in 1969 (Rohana, 1997: 58-60).

This was strengthened when Malaysia ratified the ILO Convention No.100 on equality of wages between men and women in September 1997, which decreed that women should receive equal payment to men in the public sector. However, disparity of wages between men and women still continues in the private sector (NGO Shadow Report Group, 2005). On average, women earn less than men; particularly in labour intensive industries. In this respect disabled women may not only experience environmental and attitudinal barriers at the workplace but also unequal payment. The NGOs and rights activists have demanded that the government establish a minimum wage in the private sector (NGO Shadow Report Group, 2005). In response to this, the government introduced a minimum wage for the first time in July 2012 (Ministry of Human Resource Malaysia, 2013) and as such the gender disparity in payment is envisaged as being reduced in the future. Therefore, disabled women in Malaysia are not only subjected to unequal treatment in employment mainly due to their disability, but also because of their gender status.

1.4.5 Violence and abuse

In the above sections, it has been shown how (disabled) women in Malaysia and elsewhere experienced significant challenges in many aspects of their lives. This section develops some of these ideas to explore issues around violence and abuse towards women in Malaysia that may suggest:

> Women with a disability continue to experience social oppression and domestic violence as a consequence of gender and disability dimensions. Current explanations of domestic violence and disability inadequately explain several features that lead women who have a disability to experience violent situations (Mays, 2006: 147).

For example in India there is ample evidence that disabled women experience domestic and sexual abuse although it is not officially documented. A report in Orissa, India, found that 100 percent of disabled women in the study sample were beaten at home and a quarter of women with mental health problems had been raped (Ghai, 2002). According to the 1995 UNDP Human Development Report, disabled women are twice as prone to divorce, separation, and violence as non-disabled women (UNDP, 1995). The United Nation panel discussion on preventing and ending violence against women with disabilities also found that:

> Women with disabilities experience higher rates of gender-based violence, sexual abuse, neglect, maltreatment and exploitation than women without disabilities. Violence may be experienced in the home and in other settings, including institutions, and may be perpetrated by care givers, family members or strangers, among others. Violence against women with disabilities can also take the form of forced medical treatment or procedures, including forced sterilization, the incidence of which has been documented in many countries and regions (United Nations Enable, 2012: 1).

In the context of Malaysia, women in general are more likely to be exposed to violence by their husbands or family members and also by their colleagues. A national survey conducted by Women's Aids Organisation (WAO) in 1990 to 1992 estimated that husbands or boyfriends physically beat approximately 1.8 million women or 39 percent of women above the age of 15 years (Rashidah et al., 1995). Also, 2555 cases of domestic violence were reported to the police, 165 cases reported to the MWFCD and 636 cases were recorded by the DSW (Ministry of Women, Family and Community Development, 2004). For these reasons, Malaysia enforced the Domestic Violence Act in 1994, to allow women to acquire protection against their abusers (Ministry of Women, Family and Community Development, 2007). However, many victims did not report their case, possibly because they were afraid of the abusers - often their own partners or family members - or felt circumscribed by the social stigma of being divorced and the concomitant impact on their children. Despite significant efforts over two decades by social activists attempting to address this issue, violence against women continues to rise and has proved difficult to eradicate (Ng et al., 2006).

This may be attributed to the traditional gender stereotyping in Malaysia which places women under men's responsibility. Men thus appear to have more power over women and violence against women is more likely to occur at home. Women who have children and are financially dependent on their husbands are also vulnerable and at risk of becoming victims of domestic violence (Aminah, 1998). The Women's Aid Organisation (WAO) reported that most of the women who ran away from home and sought protection with the organisation were the victims of domestic violence (NGO Shadow Report Group, 2005). As for disabled women, this can increase their vulnerability to violence and exploitation because they are arguably more likely to be in a state of physical, social and economic dependency (Driedger, 1996). For instance it is argued that disabled women, either with physical or mental disabilities, are even more vulnerable to rape crime due to their inability to fight off the rapist (NGO Shadow Report Group, 2005). Therefore this suggests that disabled women in Malaysia may have greater risk of experiencing violence and abuse in their lives.

1.4.6 Participation in politics and public life

In the Global Gender Gap Index 2012 Malaysia ranked very low - 120 out of 135 countries with regard to political empowerment (World Economic Forum, 2012). Women not only lag far behind men in attaining higher levels or decision making positions in their career paths, but they are also under-represented in politics (UN Women Regional Office for Asia and the Pacific, 2013; Women's Aid Organisation, 2012; Wan Azizah, 2002). It is observed that the number of women in parliament remains low; only two women ministers and five deputies have been given appointments in the current Malaysian Cabinet (Prime Minister's Office of Malaysia, 2013). 'Since 1957, there have never been more than three women Ministers in Cabinet at one time' (NGO Shadow Report Group, 2005: 35). This despite the fact females make up almost half of the entire population.

This low representation of women in politics is contributed to by two main factors: 1) the ever-present gender disparities between men and women in Malaysian society, 2) a political system, largely dominated by males, that is strongly constructed around ethnicity and religious-based platforms (NGO Shadow Report Group, 2005). Due to these existing issues, women are challenged when it comes to involvement in politics within such a traditional and patriarchal society.

The difficulties for women include a lack of family support, unwillingness by the political parties to sponsor female candidates, and a 'masculine model' of Malaysian politics that is still dominated by males (Wan Azizah, 2002). Malaysian society still perceives women's roles to be in the private sphere - supporting their husband and family at home - and as such it limits women's capacity for negotiating power in public domains. It is also notable that no political party in the coalition government places a quota for women to encourage their political participation (Women's Aid Organisation, 2012). Therefore, women's participation in the politics has been discouraged and circumscribed by the hostile political environment. It has been observed that 'elected members of Parliament routinely make sexist comments in and outside of parliament' (Women's Aid Organisation, 2012: 101). In February 2009, a memorandum was submitted by women members of the Malaysian parliament to complain of sexist remarks by male members towards them (Women's Aid Organisation, 2012; Ruzy Suliza, 2011). Such verbal harassment towards the female members of parliament violated the Federal Constitution of Malaysia that prohibits discrimination on the basis of gender and thus limits their equal participation in politics. Clearly women are still far short of equal opportunities for political participation which consequently undermines their status in public spheres.

Women are not only discriminated against through their unequal participation in politics, but they also encounter limited opportunities for participation in non-governmental organisations. For example, those who are within the women's rights movement face significant challenges in carrying out their projects because they are subjected to repressive and restrictive laws that curtail their freedom of speech, association and movement (NGO Shadow Group, 2005). Some women's rights activists have been detained under the Internal Security Act (detention without trial), arrested for charges of 'unlawful assembly', charged for 'maliciously publishing news', and denied entry into certain states (NGO Shadow Group, 2005; Women's Aid Organisation, 2012). Such incidents therefore violate equal rights for women's activists and prevent their effective participation in public and political life. This therefore suggests that despite women's increasing involvement in education and economic activities, they are still confined to the private sphere rather than the public domain: that they are still blocked from exercising their full agency as active agents in Malaysian society.

1.5 Conclusion

This chapter provides a brief outline to the background of Malaysia within its demographical features and unique characters. The key issues of disability in Malaysia were presented to explore how disability welfare has developed from the period of colonialism until the present. Although disability welfare was developed even before Malaysia achieved its independence in 1957, the focus of services for disabled people in the country was strongly based on the concept of 'charity' or 'caring society' that embraces the spirit of collectivism of Asian society. Thus the responsibility for looking after disabled people rests more on the families and communities rather than the government. This reinforces the idea that disability issues should be perceived within the concept of a 'welfare-based' rather than a 'rights-based' approach. It is therefore dependent on the social obligation of Malaysian people to show goodwill towards disabled people. Consequently many disabled people experience significant environmental and attitudinal barriers within society in various aspects of their lives.

The final section discussed how (disabled) women are located within the traditional Malaysian society in aspects of gender norms, access to healthcare, education and training, economic opportunities, violence and abuse and politics and public life. Due to scarcity of research on disabled women in Malaysia, it has been important to draw an understanding of Malaysian women in general. It was apparent even from this limited evidence base, that Malaysian women experienced gender inequalities due to strong traditional gender roles and stereotypes within a patriarchal society, which may further impede disabled women's lives. It was also understood that disabled women in many other countries experienced significant challenges in many aspects of their lives and there are clear interdependent links between disability, gender and culture. Therefore, this section provides a useful background towards an understanding of how Malaysian disabled women may experience their lives, living with impairment and disablement.

The following chapter therefore examines several concepts and theories that are helpful in constructing an understanding towards the lived experience of disabled women in Malaysia.

Chapter 2: Conceptualising Disability in the Global South

2.1 Introduction

Recently concerns and debates on disability in developing countries have increased. In former years such issues in developing countries received less attention from western theorists and researchers in the field (Grech, 2009: 771; Barnes and Sheldon, 2010:771). Disability theories and debates were therefore formulated, focusing mainly on developed nations while neglecting specific needs and concerns of the developing world. Consequently there has been an increasing need to understand disability within a local context, incorporating the historical, economic, and socio-cultural assumptions of developing countries.

The World Health Organisation (WHO), in its *World Report on Disability*, estimates that over one billion people throughout the world have some form of disability (WHO, 2011a). The report observed a significant increase of the prevalence of disability from 10 percent of the world's population (in the 1970s) to 15 percent by the year 2011. More significantly, disability prevalence is higher in lower income countries than higher income countries (WHO, 2011b) and is found to be more common among the poor and women (WHO, 2011a). It suggests that developing countries experience higher numbers of disabled people and thus require specific attention and tailored intervention plans. Disability research and debates are now shifting their concern from primarily focusing on developed countries to focusing on the developing world.

The term 'developing countries', previously those nations known as the 'third world', has also undergone significant changes. To date, developing countries are progressively referred to as 'Global South[8]' or 'majority world' replacing the former terminology (Goodley, 2011: 34; Barnes and Sheldon, 2010:772; Grech, 2009:771; Stone, 1999). It is argued that people in these states, which account

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[8] ''North/South' terminology came into use in the 1960s as shorthand for a complex of inequalities and dependencies: industrialised versus raw material producing countries, rich versus poor, those with military power versus those without, high technology versus low technology, and so on. 'Southern' countries are, broadly, those historically conquered or controlled by modern imperial powers, leaving a continuing legacy of poverty, economic exploitation and dependence' (Meekosa, 2011: 669).

for the vast majority of the world's population, have less access to the world's wealth and disability benefits compared to developed nations (Shakespeare, 2012; Stone, 1999). As such the term 'Global South' or 'majority world' is rather more appropriate, to avoid labelling based on their share of global resources. This thesis therefore employs the term 'Global South' to examine the current debates on disability.

It has been argued that 'disability studies, on the other hand, remains monopolised by western theorists, focused on western industrialised settings and imbued with ideological, theoretical, cultural and historical assumptions' (Grech, 2009: 771). Therefore in order to understand disability in the Global South it is important to observe the underlying issues within the local contexts, with specific reference to disability definitions, disability prevalence, and to the relationship between disability and poverty.

This chapter will also discuss the underlying principles of the social model of disability, its drawbacks, and new approaches which may provide a useful background for understanding disability in the United Kingdom (UK) and in the Global South. The chapter then moves to an alternative framework of disability research that looks into the critical realist approach. Critical realism focuses on the complexities of the disability experience, focusing on both structure and agency without overemphasising either one. Its stratified level of analysis may offer a wider perspective into disabled women's lives, particularly in Malaysia.

In brief, the chapter aims to provide useful theoretical frameworks for researching the lived experiences of women with impairment in the Global South.

2.2 Understanding disability in the Global South

2.2.1 Defining disability

It is argued that 'disability is complex, dynamic, multidimensional and contested' (WHO, 2011a:3). There is no universally agreed definition of disability across cultures, and it remains a contested term (Grech, 2009:772). In the

Global South, where each country has its own distinct characteristics, defining disability is rather difficult as the existing definition is itself generated from western concepts (Ingstad and Whyte, 1995:7). Therefore, a definition of disability employed in the North may not be appropriate for use in the South as it could be a complicated and controversial effort.

Whilst a universally agreed definition of disability is absent, it remains crucial to define disability for the sake of measurement and policy making (Grech, 2009:772). Specific criteria and classification of what constitutes disability or impairment is important in a given society to ensure proper measurements and policies for disabled people can be made. The definition of disability varies across cultures as ‘disability is defined by culture’ (Coleridge, 2000:23). Different cultures may have diverse disability definitions. For example, freckles and small buttocks among the Tuareg in Mali are considered as disabilities in marriage (Ingstad and Whyte, 1995) while in other societies, the same case may not apply. Thus, disability is a culturally constructed concept which varies amongst people across the globe, especially in the Global South.

It is argued that disability is influenced by cultural variables - it is shaped by how societies perceive disability and impairment (Shakespeare, 1994; Ingstad and Whyte, 1995; Coleridge, 2000; Riddell and Watson, 2003). Disability should be defined within a particular society from an understanding of how local people think and as a response to disability and impairment, to ensure effective intervention plans can be prepared (Coleridge 2000:23). What is suitable for a given society in the west may not be appropriate for a particular society in the east. For instance, societies in the Global South may have different and pessimistic attitudes towards disability when compared to the Global North. As such an attempt to change attitudes towards disability among people may become one of main objectives for disability policy in the Global South whereas the question of attitudes towards disability and impairment may no longer be of primary concern in developed nations.

Despite its contested nature, disability has been defined based on several approaches, predominantly those of the medical and social model perspectives. In the past, disability has been defined based on the medical or individual model of disability, which viewed disability as a result of medical conditions and individual limitations (Mont, 2007:2; Oliver, 1990). Starting from the 1970s, disability has been constructed using the social model of disability and seen as a result of environmental and social barriers (Oliver, 1990). Since then, disability has been defined either from the medical model or the social model perspective (Thomas, 1999). Recently however disability has increasingly been presented within a combination of both medical and social frameworks to provide a more balanced approach for understanding disability.

The United Nations' Convention on the Rights of Persons with Disabilities (CPRD) for instance, does not explicitly define disability as it is acknowledged as an evolving concept. The preamble of the Convention states:

> Disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (United Nations, 2006).

The Convention further states in Article 1:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (United Nations, 2006).

In addition, the WHO in the International Classification of Functioning, Disability and Health (ICF) defines disability as:

> An umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports) (WHO, 2011b).

It emphasises disability and functioning as 'outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors' that integrate between medical and social models' principles, which is seen as a functional approach (Braithwaite and Mont, 2009:220). It promotes the conceptual framework of disability employed by the WHO *World Report on Disability* in 2011 which used the 'bio-psycho-social model' approach in understanding disability (WHO, 2011a:4). Disability is thus viewed as an interaction between various factors - environmental and personal. Whereas in Malaysia, as discussed in Chapter 1, it is argued that the government defines disabled people based on the WHO definition - employing both the medical and social model approaches (Kuno, 2007; Sinnasamy, 2006; Adnan and Hafiz, 2001) - though it does not explicitly define disability.

While the definition of disability has undergone significant changes in the past few decades, with specific reference to the social model of disability, Grech argues that '[...] this social model is problematic across cultures, since it remains the product of a specific space and time, articulating the concerns of white, middle class, educated, western, disabled academics' (Grech, 2009: 772). Despite its many critics, the social model is argued to play an important role in defining disability globally as Stone claims:

> For some, the social model might be right for politicised disabled people in the west, but it should not be transferred beyond the west [...] On the other hand, the evidence from many disabled people who live in the majority world is that the social model makes sense across cultures and countries. Letters and stories printed in Disability Tribune (newsletter of Disability Awareness in Action) give strong evidence that disabled people worldwide are forming their own organisations to bring about rights-based change. It would be wrong to downplay the significance of this movement, although it is equally important to recognise how much still needs to change (Stone, 1999: 2-3).

A similar trend can also be observed in Malaysia; one that sees an increasing influence, albeit inadequate, of the social model of disability within the disabled people's movements and disability research (see, for example, Jayasooria, 2000; Kuno, 2007; Wan Arnidawati, 2013). Section 2.3 therefore will discuss the development and role of social model of disability in the Global North and the influence it might have in the Global South.

Indeed defining disability is a complex task, especially in the context of the Global South. The traditional view of disability as merely resulting from medical conditions and individual limitations has been challenged by political debates driven by the social model perspective especially in the UK (Stone, 1999). Today disability is increasingly presented as an interaction between individual dysfunctional or medical limitations and social factors that influence disabled people's lives. Yet, cultural aspects also have an important role in defining disability, especially in the Global South, and as such disability definition is a contested concept and varies across societies. Thus understanding disability in Malaysia requires disability research to be conducted within the local contexts.

2.2.2 Disability prevalence

In addition to the difficulties involved in nailing down a single definition of disability, the measurement of global disability prevalence is also problematic as reliable international data on disability is often absent (Mont, 2007:2). As discussed, global disability prevalence has shown a significant percentage increase within the four decades since 1970s and 80 percent of disabled people live in developing countries (WHO, 2011a). 'With increased longevity in all societies, disabilities associated with ageing are on the rise everywhere' (Shakespeare, 2012: 272). Although the WHO has come out with a recent global disability prevalence rate, the actual figures of disability across societies are rather difficult to measure accurately; especially in the Global South. Disability is still 'a complex multidimensional experience, poses several challenges for measurement' (WHO, 2011a:21) as this section will show.

Different societies may have different disability definitions and, as such, what is considered as a disability in a particular society may not be equally understood in another society (Ingstad and Whyte, 1995; Coleridge, 2000). Over and above the problem of definition each society may have different attitudes towards disability. For instance disability issues may not be a priority in some countries, especially in most poor societies (Coleridge, 2000:23). In poor communities disability is not usually regarded as an important aspect in community development as their main concern would be survival (Coleridge, 2000; Ghai, 2002; Shakespeare, 2012; Grech, 2012). If a deprived society cannot secure basic needs for its people, such as food and sanitation, then disability issues will not be a high priority. What is more crucial for such society is the question of survival for everyone as opposed to measuring disability prevalence among people. Thus disability incidence may be difficult to observe in some poor developing countries where attitudes to, and the priority of, disability are low.

In addition attitudes towards disability may also vary across cultures. Some societies might have positive attitudes towards disabled people whereas other societies may not. Stigma towards disabled people (Goffman, 1968; Hunt, 1966; Thomas, 2007) for example may prevent accurate measurement of disability in a particular country. Parents of disabled children who live in such a stigmatising society for instance may not report their children's impairment to the state due to societal pressure and taboo. Consequently collecting data on the actual numbers of disability prevalence in a given society may not be achievable as it is influenced by cultural obstacles.

Yet another problem is the language of disability which contains diverse types and classifications which may hinder precise measurement of disability prevalence across the globe (WHO, 2011a:21). For instance disability types are usually determined by any sensory, physical or intellectual impairment, without considering chronic health conditions as part of the category of disability (WHO, 2011a:22). As a result, in some societies, chronic health conditions which affect individuals' functions may not be regarded as a form of disability, while other societies may take this into account. Thus unanimous types and classifications of disability across countries are difficult to achieve and consequently produce dubious statistics on disability prevalence.

In the case of Malaysia, as discussed in Chapter 1, the official statistics on the prevalence and demographic characteristics of disability in Malaysia are unavailable due to the absence of a national registry on disability (Department for the Development of PWDs, 2010; Kuno, 2007:95; Shamsiah, no date). The only available data on disability prevalence is the number of disabled people who are voluntarily registered with the DSW. Although the Malaysian Population and Housing Census collect information on disability every 10 years, the data has never been published (Department of Statistics Malaysia, 2011) because the totals were far lower than the figures reported by the DSW. It is also argued that the available data underestimates the actual numbers of disabled people in the Malaysian population (Siti Zakiah, 2003).

The lack of reliable data giving disability prevalence in Malaysia creates a major obstacle to formulating effective disability policies and plans. Accurate measurement of disability prevalence is crucial in identifying developmental strategies to improve the well-being of disabled people in the state (WHO, 2011a:24). Actual numbers of disabled people across residential areas, both in rural and urban regions, are also important to ensure that disabled people are getting adequate services and equal participation in society. Therefore, measuring the prevalence of disability, especially in the Global South, is a very complicated yet pivotal issue.

2.2.3 Poverty and disability

It is argued that disability has been often associated with poverty but few empirical studies examine the relationship between these two in developing countries (Groce et al., 2011; Braithwaite and Mont, 2009). Sen (2009) and Elwan (1999: i) suggest a two-way relationship between disability and poverty as ‘disability may increase the risk of poverty and poverty may increase the risk of disability’ (Sen, 2009). The World Bank indicates that poverty and disability have a strong mutual relationship in which poverty may lead to disability through poor health care, malnutrition and difficult living conditions (The World Bank Group, 2011).

The World Bank Poverty Assessments review found that many developing countries acknowledge that there is a strong relationship between poverty and disability but little data regarding this phenomenon is available (Braithwaite and Mont, 2009:219). The World Bank further estimated in 1999 that in developing countries, about 20 percent of those who are living on or below poverty line were disabled people (Levinsohn, 2002). For example in Uganda, ‘at least 2.4 million disabled people remain poor’ (Lwanga-Ntale, 2003:1): this shows that disabled people are liable to live in poverty or that poor people are at greater risk of developing an impairment, especially in the Global South.

Low economic status hinders people from acquiring proper medical treatment, prevents them from having sufficient nutrition, especially for children, and makes them vulnerable to many dangers by living in poor neighbourhoods. Likewise disability may herald the onset of poverty by preventing disabled people from full participation in social and economic activities (WHO, 2011a:10; The World Bank Group, 2011). For instance disabled children have less opportunity to attend school (Filmer, 2008; Jonsson and Wiman, 2001) and they may become an economic burden on families and society (Jonsson and Wiman, 2001:1). Exclusion from education may reduce employment opportunities among disabled youth and thus increase the risk of poverty. Disabled people are also more likely to experience unemployment and discrimination in employment (WHO, 2011a:10). Furthermore they may receive low wages, marginal promotion prospects and encounter a lack of access to transportation.

In Malaysia, as discussed in Chapter 1, there is evidence that disabled children experience barriers in education. Disabled children in rural areas, regardless of the type of disability, have fewer opportunities to attend formal education (Kuno, 2007:100). Disabled children with severe physical impairment, particularly from rural areas, often encounter barriers in terms of accessibility and a dearth of those facilities provided by mainstream schools (Ong et al., 2002). Also in terms of employment findings demonstrate that employment rates among disabled people are low despite various employment policies and incentives provided by the government (Ramakrishnan, 2007; Mubarak, 2006; Faridah, 2003; Jayasooria, 1997). Nevertheless little is known of how the mentioned phenomenon may be associated with the ‘two-way relationship between disability and poverty’ as empirical data on this is unavailable.

The United Nations’ Convention on the Rights of Persons with Disabilities (CPRD) acknowledges that the majority of disabled people live in poverty and effective measures should be taken by member states to eradicate poverty among disabled people (United Nations, no date). The CPRD also emphasises the promotion of participation, and the enhancement of the well-being, of disabled people through international developmental agendas. Disability should be incorporated in all development programmes and should not be regarded as ‘a stand-alone thematic issue’ (WHO, 2011a: 11). The state should always include disability in their national development policies and programmes. Thus it suggests that the collection of empirical data on the vicious circle of poverty-disability is crucial, especially in the context of Global South countries such as Malaysia.

2.3 The social model of disability

The above sections have presented many examples of disability issues in the Global South (and Malaysia) and they suggest that a materialist perspective may offer a useful outlook of disability within the local context. This section therefore will outline some principles of the social model of disability that may be relevant to the understanding of disability in the Global South. The underlying criticisms and limitations of this model will also be discussed subsequently.

It is argued that the social model is regarded as one of the keystones in the development of disability studies (Oliver, 2009; Thomas, 2007), and it has been called 'the big idea' of the disabled people's movements in the UK (Hasler, 1993). The social model approach focuses 'on the social and environmental barriers faced by disabled people' (Watson, 2012b: 194) and the concept that people are disabled by society not by their bodies (Oliver, 1990). The underlying principles of the British social model of disability was taken originally from the Union of Physically Impaired Against Segregation (UPIAS) from its *Fundamental Principles of Disability* document in 1976 (Oliver, 1996).

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1976: 14).

It challenged the traditional understanding of disability that was viewed 'as an individual medical problem or 'personal tragedy' in western culture' (Barnes, 2012: 12). Oliver argues that the individual model of disability places the 'problem' within the individual and assumes that individual's disability causes functional limitation and psychological losses (Oliver, 1990). People are therefore disabled by their inability to function (Hughes and Patterson, 1997) and thus it needs medical and psychological intervention to return people to 'normality' (Oliver, 1996). The individual model has influenced the rehabilitation and educational provisions for disabled people where the primary focus was to assist people in overcoming their individual problems so that they could fit into society (Oliver, 1990). The social model then shifted the ‘problem’ from the individuals to society by making a clear distinction between impairment and disability as found in the UPIAS document:

> To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (UPIAS, 1976: 14)

Disability is therefore conceptualised as a form of social oppression that locates the problem of disability squarely within society:

> Hence disability, according to the social model, is all the things that impose on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport system, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society (Oliver, 1996: 33).

Instead of focusing on impairment within the individual, disability is seen as socially constructed through the ways that society excludes disabled people from full participation within society (Barnes, and Mercer, 2010). It thus shifts the attention away from the individual to disabling barriers and attitudes; as Finkelstein asserts:

> Once barriers to the reintegration of people with physical impairments are removed the disability itself is eliminated. The requirements are for changes to society, material changes to the environment, changes in environmental control systems, changes in social roles, and changes in attitudes by people in the community as a whole. The focus is decisively shifted to the source of the problem – the society in which disability is created (Finkelstein, 1980: 33).

The social model is regarded as having a crucial role in the disability movement as a political strategy for the removal of barriers and as emancipation for disabled people (Oliver, 2009; Shakespeare, 2014). As a result disabled people were able to understand that it was society that was at fault and that they were not (Crow, 1996). Therefore the ‘solution’ to disability was not conceived as rehabilitation for the individual but involved changes to attitudes and policy formulation to promote a barrier-free society. The social model develops an understanding of disability as a social phenomenon based on a socio-economic structure of society that focuses on the capitalist mode of production (see Thomas, 1999: 125-135). For example Oliver claims that disability is ‘defined or culturally produced solely in terms of its relationship to the mode of production’ (Oliver, 1990: 2). Capitalist society, in which the labour market requires the notion of ‘able-bodiedness’ as part of a workforce, reinforced economic marginalisation for disabled people. Through the development of wage labour, disabled people could no longer meet the demands of capitalist market and thus they needed to be ‘medicalised’ in order to fit into the economic structure of capitalist society (Oliver, 1990; 1996). Therefore the only way to overcome such social injustice and oppression towards disabled people was to bring change at the structural (societal) level.

2.3.1 Criticisms of the social model of disability

Whilst the social model has appeared to be a fundamental political principle in disability studies and disability movements in Britain and elsewhere (Stone, 1999; Grech, 2009), it has received numerous criticisms from within and outside its paradigm. It has been criticised for focusing on structural disabling barriers and ignoring the impact of impairment on individuals (Morris, 1991; Crow, 1996; Shakespeare and Watson, 2001), and failing to take account of experiential and cultural aspects of disability and identity (Riddell and Watson, 2003; Barnes and Mercer, 2003).

Amongst the main criticisms to the social model is its impairment/disability distinction. As discussed the social model does not acknowledge impairment as the cause of disability, and disability is seen as merely the result of societal barriers imposed upon disabled people (Oliver, 1996). However for many critics the key problem is how to identify disability without taking impairment into account. Shakespeare for instance argues that recognition of impairment in disability studies is important. It is crucial to understand the complexities of disabled people's collective experience as impairment influences the individual in various ways (Shakespeare, 2006; 2014). For many commentators impairment is not consistently neutral to disabled people's experiences as it can be unpleasant and difficult for some disabled people due to their own bodily incapacity (Crow, 1996). To deny the presence of impairment in disability studies is in fact problematic (Shakespeare and Watson, 2001: 14). It is vital to the understanding of disability, as Hughes and Patterson suggest, to include an 'embodied notion of disability' as a means of developing a sociology of impairment (Hughes and Paterson, 1997).

Shakespeare and Watson (2010) further argue that the way people perceive their quality of life depends on various subjective innate factors correlated to their impairment as well as their personality. Both impairment and a disabling environment affect disabled people's life and as such impairment should be integrated into the understanding of disability as a whole (Crow, 1996; Shakespeare and Watson, 2001; Shakespeare, 2006). Instead of claiming 'people are disabled by society not their bodies', Shakespeare and Watson suggest that 'people are disabled by society and by their bodies' (Shakespeare and Watson, 2001; Shakespeare, 2014). Abberly (2002) also suggests that disability studies should examine the whole experience of disability including impairment and differences between impairments, and not only focus on the negative effects of barriers and its removal.

Feminist writers such as Jenny Morris, Liz Crow and Sally French criticised the failure of social model to include and appreciate the problems associated with personal experience of having an impairment (Shakespeare and Watson, 2001; 2010; Thomas, 2007). French argues that social manipulation per se cannot be the possible solution for some disabled people with a specific impairment (French, 1993: 135) and therefore incorporating personal experience into disability research is important. Morris claims that the social model has been dominated by male protagonists and this has led to the dismissal of the personal experience of disability and impairment because it was seen as not supporting the barriers' removal:

> […] there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are *entirely* socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying (Morris, 1991: 10, emphasis in original)

Disabled feminists therefore argued that the 'personal is political' and it was crucial to take account of personal experience which relates to bodily experiences in the understanding of disability (Morris, 1992; Thomas, 2007).

Another criticism focuses on inability of the social model to incorporate differences among disabled people; especially diversities of gender, 'race', type of impairment, or sexuality (Thomas, 2002: 369) and culture (Shakespeare, 1994; Riddell and Watson, 2003). Shakespeare and Watson (1998) argue that differences between disabled people in socially constructed categories, like gender, 'race', class and sexuality, are important facets in the collection of disabled experience. To understand the real issues behind the disabled experience is to be able to collectively examine underlying features in these social disparities (Corker, 1999: 634). For example a woman may have a different experience as compared to a disabled man; or an Asian disabled gay man may have a different world experience from a white disabled gay man. Studies conducted on disabled women in the United States (US) found that the women had low levels of participation and low self-esteem and this was argued as two effects of impairment: a sexism and disabled female 'plus factor' that is unique in nature (Hanna and Rogovsky, 2006). Moreover disabled women in the Global South, as in India for instance, may be even more 'disadvantaged' as a result of gender, poverty, caste and class (Ghai, 2009: 283). As each culture creates an individual perception of disability, race, gender role or sexual orientation, so every individual carries a unique point of view depending on his or her societal upbringing. Therefore, research involving disabled people should acknowledge diversity and cultural differences among them as unique elements that may be possessed by each individual.

The social model of disability has also been criticised for its emphasis on disabled people’s identity as a homogenous group. Social model writers represent disabled people as a group who share a comparable experience of ‘disablism’ who, it is believed, can work together to form a social revolution and create a barrier free environment (Thomas, 2007: 76). Such a perspective constructs people, irrespective of any kind of impairments, as having one ultimate shared identity – as disabled people. However this is not always true as Watson in his studies found that only three out of 28 respondents identified themselves as disabled; while the majority of respondents being interviewed did not relate disability to their self-identity (see Watson, 2002). ‘Many disabled people do not want to see themselves as disabled, either in terms of the medical model or the social model’ (Shakespeare and Watson, 2001: 20). Some groups of people with other types of impairment, such as Deaf people, do not see themselves as disabled but perceive themselves as being a linguistic minority (Corker, 1998). Similarly people with mental health problems self-define as ‘psychiatric system survivors’ rather than as disabled (Beresford, 2000). The feminist approach also acknowledges that disabled people do not represent a homogeneous social group (Shakespeare, 2006: Thomas, 2007). As such the central belief of the social model, incorporating all people with impairment as having disabled identity, was rather misleading.

Shakespeare and Watson further argue that the concept of a barrier-free utopia designed in the social model of disability is problematic and demanding (Shakespeare and Watson, 2010: 62; Shakespeare, 2006: 45; 2014). The social model is seen as having an impractical belief in claiming that all barriers are created by society. If such barriers are eliminated people will no longer experience barriers in their life, irrespective of what type of impairment they may have. Such a central belief in creating a barrier-free world is only applicable to physically and visually impaired people whose central problem may lie in their disabling environment. However other types of disabled people who have invisible impairments, such as individuals with learning difficulties, may not experience the world in the same manner as physically or visually impaired individuals. For people with learning difficulties the barriers may not be imposed on them from their surrounding environment, but by their own limitations regarding mental capacity. If the barriers are removed they still cannot fully participate in society as their lack of mental capacity will impact on their interaction with others in many parts of their life (Shakespeare and Watson, 2010; Shakespeare, 2006; Thomas, 2007). Goodley (2001) added that this is the time,

> […] to move from the social model of disability to mutually inclusive social theories of disability and impairment that are open and inclusive to people who have been labelled as having ‘learning difficulties’ (Goodley, 2001: 225).

Therefore the creation of a barrier-free utopia for all disabled people, as advocated by the social model, is impossible to achieve as different types of impairment require different interventions and resources from both society and disabled people themselves.

In response to the many criticisms aimed at the social model of disability Oliver cites his justifications as the following. Referring to the highly debated issue of whether there should be separation of impairment from the concept of disability Oliver argued that the social model was not intended to address the personal experience of impairment but rather it is designed for the collective disablement experience. He argues that personal experience of impairment by disabled people is not adequate to establish a political movement in search for justice from the state. Oliver used his limited functional experience as a case study to exemplify how his impairment has had little effect on the welfare state (Oliver, 2004: 24). Following criticisms of the failure to incorporate varying social categories of disabled people, Oliver again argues that the social model can integrate those categories into the model. He challenges social model critics to try filling the gap and bring in what they found lacking in the model (Oliver, 2004: 25). Finally Oliver maintains that social model is just a model and not a theory of disability. So, for him, the social model cannot be blamed for theoretical inadequacy as it is not a theory after all (Oliver, 2004: 26; 2009).

However Shakespeare and Watson argue that ‘the ‘strong’ social model itself has become a problem, and that it cannot be reformed’ (Shakespeare and Watson, 2001: 13) and that it has a tendency to become a litmus test (Shakespeare and Watson, 2010). For them the social model orthodoxy is no longer useful in disability studies and a new model should be developed rather than attempting to repair its inadequacies. They further claim that the social model has been widely accepted only in the UK and has not been used for social reform in the US or other nations (Shakespeare and Watson, 2001: 14). It is contended that it is outdated and a fresh comprehensive model of disability incorporating both medical and social framework should be highly encouraged. Shakespeare in his new edition of *Disability Rights and Wrongs Revisited* outlines imperative criticisms of the social model and suggests that multi-factorial accounts for understanding disability are more helpful than reductionist accounts between the medical model and the social model (see Shakespeare, 2014). Indeed all radical critiques of the social model of disability as discussed above have set fundamental challenges for the survival of the social model in the present day.

2.3.2 Impairment effects and psycho-emotional disablism

In response to many critiques of the social model of disability Carol Thomas, a feminist disability writer, has developed a new materialist approach to disability: what she terms as a relational understanding of disability (Watson, 2012b). She reformulated the UPIAS definition of disability thus:

> […] is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being (Thomas, 1999: 3)

In her later work she redefines ‘disability’ as ‘disablism[9]’ (see Thomas, 2007: 73). Thomas (1999: 42) argues that in the UPIAS social relational approach it states that ‘disability’ arises from the social barriers imposed on people with impairment, however some restrictions (disadvantages) which may be directly associated with having an impairment are not addressed. Therefore she ruled out this restriction of activity as a result of having an impairment (physical, sensory or intellectual) which may become the marker of other restrictions of activity that constitute ‘disability’ as ‘impairment effects’. The concept of ‘impairment effects’ refers to:

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[9] ‘Disablism’ is introduced by Paul Abberley (1987) and refers to the social beliefs and actions that oppress/exclude/disadvantage people with impairments. It is used widely in disability studies that connote the meaning of social oppression (Thomas, 2007).

> […] restrictions of bodily activity and behaviour that are *directly attributable* to bodily variations designated ‘impairment’ rather than those imposed *upon* people *because* they have designated impairments (disablism) (Thomas, 2007: 136, emphasis in original).

To describe ‘impairment effects’ she explains that, for example, her inability to hold a spoon or a saucepan in her left hand is an effect of her impairment but this does not constitute ‘disability’ in the social relational sense. However these ‘impairment effects’ (restriction of activity due to her own impairment) may lead to ‘disability’ (social restriction) as people may discriminate against her in employment by not taking her into work and might not make reasonable adjustments to accommodate her impairment needs. Nevertheless Thomas contends that ‘disability’ cannot be ruled out as purely social, or cultural and ‘impairment effects’ as biological or natural, because both ‘interact and meld together in a holistic fashion’ (Thomas, 1999: 43). The ‘impairment effects’ are important to the study of disability as acknowledgment of their presence is crucial for comprehensive understanding of those biological, social and cultural aspects in disabled people’s life that challenge the strict materialist model of Oliver and others. This notion of ‘impairment effects’ introduced by Thomas has been regarded as very influential in British disability studies (Goodley, 2011).

In addition Thomas also introduced the concept of ‘psycho-emotional disablism’ to address the failure of the social model to recognise the feminist’s interest in ‘the personal’ and ‘the experiential’ of disability (Thomas, 2007). The social model has emphasised the socio-cultural barriers that focus on the ‘public’ experiences of oppression and neglect the ‘personal’ experiences of oppression which operate at the emotional level (Thomas, 1999). Therefore, she employs ‘psycho-emotional disablism’ which she refers to as:

> […] the intended or unintended ‘hurtful’ words and social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments. It also involves the creation, placement and use of denigrating images of ‘people with impairments’ in public spaces by the non-disabled (Thomas, 2007: 72).

This form of disablism may have profound impact on the psychological and emotional wellbeing of people with impairment that work along with the structural dimension of disablism (Thomas, 2007). ‘Psycho-emotional disablism’ may give a negative impact on individuals' self-esteem so that they can feel worthless, useless and troublesome (Reeve, 2002; 2006). Thomas' notion of 'psycho-emotional disablism' was later extended by Donna Reeve (2006; 2012). Reeve clearly differentiated between two forms of social oppression: structural disablism and psycho-emotional disablism. The structural disablism operates at the level of structural barriers such as inaccessible environments, discrimination and exclusion; while psycho-emotional disablism operates at the psycho-emotional wellbeing of disabled people (Reeve, 2012). The concept of 'psycho-emotional disablism' was further divided into two forms: direct psycho-emotional disablism and indirect psycho-emotional disablism. Reeve asserts:

> Direct psycho-emotional disablism arises from relationships that the disabled person has with other people or themselves and is the most important form of psycho-emotional disablism. However, it is also possible to identify examples of indirect psycho-emotional disablism which emerge alongside the experience of structural disablism (Reeve, 2012: 79).

Thomas's work on 'impairment effects' and 'psycho-emotional disablism' aims to provide a complete understanding of disability experiences within which she intends to incorporate both the individual limitations and social oppressions (Thomas, 1999; 2007; Watson, 2012b). This approach allows for an integrated understanding of disability experience that she denotes as 'barriers to doing' and 'barriers to being' (Thomas, 2007). For 'barriers to doing' she refers to how the structural dimensions of disablism (socially imposed restrictions on activity) affects what people can 'do': for example inaccessible environments can prevent people with physical impairment to access buildings and social spaces. On the contrary 'barriers to being' refers to how psycho-emotional disablism (socially engendered undermining of one's psycho-emotional wellbeing) affects who people can 'be'; for instance coping with stares from strangers at public spaces can undermine the self-esteem of people with impairment and leave them feeling discredited (Thomas, 1999; 2007; Reeve, 2012).

Whilst the concept of 'impairment effects' and 'psycho-emotional disablism' may offer a fruitful understanding in disability studies, they are not without their limitations. Although Thomas's notion of 'impairment effects' has been significantly recognised within disability studies, Shakespeare and Watson (2010) argue that it is difficult to distinguish what constitutes impairment effects and what is disablement because these two are interrelated: Thomas (2010) also acknowledges this fact. They envisage that impairment and disablement may become dual systems rather than a fluid continuum of disability experiences (Watson, 2012b). Moreover Shakespeare argues that ‘the role of impairments in contributing to social disadvantage is [still] largely ignored’ (Shakespeare, 2014: 21) in the social model and thus it does not contribute to the development of disability studies. In regard to the notion of ‘psycho-emotional disablism’ it is suggested that social oppressions still dominate the understanding of disability rather than a consideration of the role of impairment or chronic illness as additional possible causes of disability experience (Watson, 2012b). Shakespeare argues that besides inter-personal encounters and social relations (along with physical and economic barriers), impairment and illness also can undermine psycho-emotional wellbeing of people with impairment (Shakespeare, 2014: 23). This suggests that both disability and impairment have psycho-emotional effects.

Therefore instead of focusing only on the materialist point of view emphasising the social oppression at the socio-structural level a wider understanding of disability experience is needed, especially in the context of the Global South. In order to understand the essence of the lived experience of women with impairment in Malaysia the framework of analysis should be able to incorporate the complexity of Malaysian society, especially in terms of historical and socio-cultural backgrounds in relation to gender and impairment. For that reason, the next section will explore the critical realist approaches to disability that may offer a broader framework of analysis for disability studies in the Global South.

2.4 The critical realist approaches

As argued earlier disability is a contested term as it varies across cultures and societies (Grech, 2009; Ingstad and Whyte, 1995; WHO, 2011a; Coleridge, 2000). ‘Disability cannot be reduced to a singular identity: it is multiplicity, a plurality’ (Shakespeare and Watson, 2001: 19). It cannot be assumed to simply represent a social oppression as it tends to be more complex. In view of that it is fruitful to understand the disability experience from multi-factorial accounts rather than reductionist accounts (Shakespeare, 2014). As Watson writes:

> A social understanding of disability is necessary and research should focus on and engage with societal attitudes and structural and experiential factors and not only document but also explain criticize and, if appropriate, provide a means to undermine and challenge oppressive or discriminatory factors. If the research starts out with a pre-existing commitment to a particular understanding it will prevent reflexivity, and an exploration of who defines and controls the research questions and how they do it can become blurred (Watson, 2012a: 101).

This section therefore will explore the critical realist approaches to disability in search for an alternative framework of research to understand the lived experiences of disabled women in Malaysia. This section draws upon works by Williams (1999), Danermark and Gellerstedt (2004), Shakespeare (2006; 2014) and Watson (2012a; b). Critical realism emphasizes a non-reductionist perspective (Danermark and Gellerstedt, 2004) as a way of understanding the social world. The critical realists understand phenomena exist whether or not we have conscious knowledge of them, yet the existence of phenomena (ontology) should not be conflated with the knowledge about them (epistemology) (Thomas, 2007; Watson, 2012a; Shakespeare, 2006). As Bhaskar argues ‘things exist and act independently of our descriptions, but we can only know them under particular descriptions’ (Bhaskar, 1975: 250 cited in Shakespeare, 2014: 73). For example impairment has always existed and has its own experiential truth even when we have different opinions or attitudes about it across cultures (Shakespeare, 2006). As such we cannot deny the existence of impairment and its experiential reality as it is embodied within us.

‘In critical realism, social science research is concerned with exploring how agency is influenced by structures and vice versa, without overemphasizing either agency or structure’ (Watson, 2012a: 102). Both agency and structure are equally important as they are shaped and reshaped by one another across time (Williams, 1999). A critical realist approach thus allows us to move beyond debates about what is disability and impairment and how they should be defined and what is the relationship between impairment and disablement (Watson, 2012a). This non-reductionist approach enables us to explore the experiential reality of impairment and to observe the possible daily problems associated with living with impairment (Scambler, 2005). Critical realism focuses on both structural barriers to inclusion and individual agency, which gives value to the different dimensions of disability experience (Shakespeare, 2006). It thus permits us to avoid the classic arguments of the medical model versus social model in establishing a 'true' understanding of the disability phenomenon.

Therefore the critical realists' approaches seek to explore different levels of analysis in the complex disability experience as Williams stresses:

> Disability [...] is an emergent property, located, temporally speaking, in terms of the interplay between the biological reality of physiological impairment, structural conditioning (i.e. enablements/constraints), and socio-cultural interaction/elaboration (Williams, 1999: 810).

Disability is thus being examined from different angles of analysis and not from a single lens of inquiry, for which Danermark and Gellerstedt argue:

> This implies that injustices to disabled people can be understood neither as generated by solely cultural mechanisms (cultural reductionism) nor by socio-economical mechanisms (economic reductionism) or by biological mechanisms (biological reductionism). In sum, only by taking different levels, mechanisms and contexts into account, can disability as phenomenon be analytically approached (Danermark and Gellerstedt, 2004: 350).

Disability can also be understood as an interaction, as suggested by Shakespeare:

> [...] disability is always an interaction between individual and structural factors. Rather than getting fixated on defining disability as a deficit or a structural disadvantage or alternatively a product of cultural discourse, a holistic understanding is required. Put simply, the experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself (Shakespeare, 2014: 75).

The intrinsic factors may include the nature and severity of impairment, personality, individual attitudes, abilities and qualities; while the extrinsic factors can be the attitudes and reactions of others, environment, economic, policy and cultures (Shakespeare, 2006; 2014). Nevertheless the contextual factors (extrinsic) may influence the internal factors (intrinsic): 'impairment may be caused by poverty or war, personality may be influenced by upbringing and culture, etc' (Shakespeare, 2014: 75). For example a girl in India may become blind due to trachoma because her family is too poor to get her antibiotics; then she may not have a formal education because of her family's poverty and a cultural upbringing that places less value on females' education as compared to males. As a result of her impairment and low education she may have restricted opportunities for wider economic and social activities. Therefore disability is always an interaction between different contextual and intrinsic factors that vary across individuals, cultures and locations.

Likewise disability can be examined within a stratified or laminated system (Collier, 1998) in which Watson (Watson, 2012a; b) cites the work of Bhaskar and Danermark (2006) who suggest that disability can be explored at different levels:

- physical
- biological
- psychological
- psycho-social and emotional
- socio-economic
- cultural
- normative

This stratified system of analysis offers a practical understanding of the disability experience. For example Shakespeare and Watson (2010) suggest a laminated schema of interventions for research into spinal cord injury that covers various spheres of lives including the political, cultural, social, educational, economic, environmental, psychological, and technological; and reaching to include therapy, nursing, medicine, prevention and public health and basic science. This schema of intervention which examines manifold aspects of lives can be applied to different groups of disabled people or categories of impairment. For example it can be used for research into childhood disability (see Watson, 2012b) and spinal cord injury (see Shakespeare and Watson, 2010). Thus the critical realist framework may offer a holistic approach to research into disability, particularly with respect to women with impairment, because it allows for a complex level of analysis to be employed.

2.5 Conclusion

This chapter has explored several issues pertaining to disability in the context of the Global South; i.e. disability definition, disability prevalence, and the relationship between poverty and disability. It has discussed how attaining an understanding of disability in the Global South is complex and challenging yet pivotal. Although the majority of people with impairment live in the Global South, theories and approaches on disability are still dominated by the Global North. Therefore it is suggested that research involving people with impairment should incorporate the local historical, economic and socio-cultural contexts without denying the need for disabled people's liberation.

It was argued that in order to facilitate the emancipation of disabled people, the disability approach should embark on a political strategy - the social model of disability. Undeniably the social model has played a significant role in the development of the disability movement and disability studies in the UK and has started to gain important recognition in the Global South. Nonetheless the 'strong' social model approach has received various critiques from within and outside its paradigm, particularly on issues of impairment/disability distinction, and its failure to incorporate differences, such as gender, culture and category of impairment, amongst people with impairment. The social model has also been criticised for focusing only on social oppression, limiting the scope of analysis into the medical model versus social model, and placing emphasis only on the material perspective. Although new concepts such as 'impairment effects' and 'psycho-emotional disablism' have been introduced by Thomas (Thomas, 1999; 2007), there is still a focus on social oppression. Whilst this model has been useful for assisting the liberation of disabled people, it does not permit for wider analysis into disability experience especially for disabled women. Therefore an alternative approach of research is needed to embrace the complexity of disabled people's lives in the Global South.

The last section therefore discussed the critical realist approaches to disability in an attempt to search for a broader approach to disability research. Critical realism is useful in providing a wider perspective on disability research, especially for a complex level of analysis such as that required with women with impairment. In Chapter 1 it was discussed how disability issues and women are located within Malaysian society. It revealed that inaccessibility issues are still paramount in the lives of many disabled people, especially those with mobility impairment. At the same time it was argued that the societal and governmental attitudes towards disability and disabled people are largely based on the 'charity' concept rather than the 'right-based' framework. Consequently many people with impairment are excluded from wider economic and social participation, especially those living in rural areas or in poverty. In this respect the social model perspective is useful to provide a background for understanding social oppression towards people with impairment and the structural barriers that impede disabled people's lives. Nevertheless, the social model is unable to offer a wider understanding of the complexity of Malaysian (disabled) women's lives and therefore the critical realist approach is seen as more helpful.

Chapter 1 also revealed that women in general experience significant barriers and discriminations in terms of gender norms, access to healthcare, education and training, economic participation, violence and abuse and participation in politics and public life. Many women in Malaysia are still unable to exercise their agency despite increasing involvement in the economic and social participation due to the strong traditional gender roles and gender divisions within a patriarchal society. As such disabled women in Malaysia may not only be restricted from equal opportunities in society due to structural barriers but also they may also be disadvantaged by the cultural and individual barriers. They may experience a stratified level of disability experience that suggests an interaction between the individual factors and contextual factors. It is also vital to observe that Malaysia is made up of multiple ethnic groups and religions and thus it has varied cultural beliefs and practices. Therefore it suggests that a simple level of analysis is inadequate and in order to understand the essence of Malaysian disabled women's lives; any analysis should be able to embrace this cultural diversity.

In conclusion, while the social model of disability offers a useful background for understanding social oppression and structural barriers, it has limited scope of analysis. Therefore, critical realism may provide a wider perspective on disabled women's lives especially within the complexity of Malaysian society.

Chapter 3: Methodology

3.1 Introduction

The aim of this study was to explore how women with mobility impairment in Malaysia experienced their lives. As indicated in the introduction, little is known about the lived experience of Malaysian women living with impairment and disablement in Malaysia.

This chapter focuses on the methodologies and methods employed in this research and the way they were used to generate narratives about ‘living with impairment and disablement’ in Malaysia. It is presented in a reflexive manner that incorporates my personal insights into the research process. The first section discusses the main issues revolving around researching disability in the Global South. It looks into the historical development of disability research in the Global North that may influence disability research in the Global South. This section also describes the research approaches used in this study: qualitative methodology and narrative research. The second section explains about data collection methods that involve ethical considerations, the research participants and recruitment strategies, qualitative interviewing, research diaries and field notes, and a reflection regarding the research process between my participants and me. It explores main issues arising from this cross-cultural research. The final section examines a detailed account of data analysis and interpretation that deliberates on how the participant summaries, transcript construction, Malay/English translation and data management were analysed and interpreted. This section also discusses language translation dilemmas arising from this cross-language research.

This chapter can be summarised as an examination of the research process from the perspective of both researcher and participants: a process which is both reflexive and self-reflective.

3.2 Research Methodologies

3.2.1 Researching disability in the Global South

Disability research in the Global South is relatively new - still in its infancy - and in many developing countries there is little or no research on disability (Stone, 1999; Hertley and Muhit, 2003). Grech (2009) argues that little is known about disability in the Global South and that disability studies are dominated by western theories, ideologies, cultural and historical assumptions. The ideas about disability in the Global South are therefore imported from the western context and local ideologies on disability are often absent. Whilst the WHO *World Report on Disability* (2011) attempts to fill this gap, Shakespeare asserts that:

> In many areas, we lack solid evidence about the lives of people with disabilities in developing countries and the problems they face. Frequently, and for the best of motives, numbers – on education, on poverty, on health – are used for advocacy purposes, but are not supported by good research, or sometimes any research at all (Shakespeare, 2012: 271).

This section aims to present an overview of how disability research developed in the Global North and how this may influence disability research in the Global South. Initially research into disability in the Global North was dominated by the positivist research paradigm until the start of the 1990s (Oliver, 1992). The positivist research paradigm has been criticised for believing that all knowledge should be politically neutral and objective and obtained independently of the researcher (Blaikie, 1993). Feminists argue that this is not always possible because knowledge production is influenced by the researcher's values (Ramazanoglu and Holland, 2002).

For example one of the most influential pieces of disability research in the UK by Miller and Gwynne (1972), on the life of residents of the Le Court Cheshire Home, was heavily criticised for being biased and betraying the residents' trust (Hunt, 1981). Paul Hunt and other residents of the care home requested that Miller and Gwynne conduct research to examine how physically disabled people had been denied any choice or control in their lives in the institution and were segregated from the mainstream society. They hoped that the research would support their autonomy resulting in greater involvement in the residential management. Instead of supporting the residents' wish for greater control over their lives in the care home, Miller and Gwynne's research report (1972) suggested that one of the key roles of the residential institution was to prepare the residents for their actual death. This evoked anger amongst the residents and thus Hunt and his colleagues politically and intellectually challenged the report leading to the formation of the Union of the Physically Impaired Against Segregation (UPIAS). UPIAS then published *The Fundamental Principles of Disablement* document that challenged the existing research paradigm and the social oppression of disabled people. It contributed to the development of a social model of disability in the UK and underlined the need for a new research paradigm which Mike Oliver defined as the emancipatory research paradigm (Watson, 2012a; Barnes and Mercer, 1997). Oliver argues:

> Disability research should not be seen as a set of technical objectives procedures carried out by 'experts' but part of the struggle by disabled people to challenge the oppression they currently experience in their lives (Oliver, 1992: 102).

Therefore disabled people and scholars in disability studies have argued for the use of an emancipatory paradigm in disability research to challenge the social oppression of disabled people (Stone and Priestley, 1996; Oliver, 1992) and to promote the empowerment of disabled people so that an alternative social policy could be established for their improvement (Barnes, 2003; Oliver, 1992). This paradigm is influenced by the critical theory and feminist praxis (Danieli and Woodhams, 2005) that is located within the social model of disability (Reeve, 2008). It seeks the participation of disabled people in disability research running parallel with the slogan of disability movements; 'nothing about us without us' (Walmsley, 2005: 735). It emphasises the participation of disabled people throughout the research process, and involves the politicisation of their own experience to generate disability knowledge and to strive against the social oppression displayed against them (Barnes and Mercer, 1997; Beresford and Evans, 1999).

For example, Stone and Priestley identified six core principles of the emancipatory research:

> 1. The adoption of a social model of disablement as the epistemological basis for research production;
> 2. The surrender of claims to objectivity through overt political commitment towards the struggles of disabled people for self-emancipation;
> 3. The willingness to only undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;
> 4. The evolution of control over research production to ensure full accountability to disabled people and their organizations;
> 5. Giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences;
> 6. The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.
>
> (Stone and Priestley, 1996: 706)

Following the significant role played by the emancipatory research paradigm in the western context, research into disability in developing countries also experienced a similar trend. There have been increasing efforts in recent years to employ emancipatory research paradigms coupled with the social model of disability when conducting disability research in the Global South (Grech, 2009:775; Turmusani, 2004:3). It is seen as vital that this approach be utilised in developing countries where disabled people experience discrimination and oppression. This political research paradigm is argued to provide a better prospect for disabled people in the Global South (Grech, 2009). Whilst the emancipatory approach played a significant role in disability research in both the Global North and the Global South writers, such as Shakespeare (1997; 2006), Danieli and Woodhams (2005) and Watson (2012a), have questioned its suitability as a research methodology. For example, not all researchers in the field of disability conducted their studies with the explicit political aim of highlighting and providing evidence of the social oppression experienced by disabled people in their everyday lives. As Shakespeare claims:

> My current research concerns sexuality and disability, and is not emancipatory research. I hope it is research which reflects the reality of disabled people, and which acts as validation and affirmation for disabled people who read the book. It may have some indirect policy outcomes, but I do not think it should be judged on instrumental grounds, and I defend the right of researchers to undertake research and develop theory for its own sake. This is not the same as offering researchers *carte blanche* to parasitise disabled people' s experience and develop careers on the back of disabled people's lives (Shakespeare, 1997: 118).

The emancipatory research paradigm, located within the social model of disability, has limited the scope of disability research into the political dimension of disability experience. It seeks to meet the demands laid down by the emancipatory research approach that has been directed towards eliminating the systematic and institutional discrimination towards disabled people (Barnes and Mercer, 2010). Although this is important, it creates a problematic research agenda that focuses merely on social inequalities and tends to neglect other aspects of disabled people's lives (Danieli and Woodhams, 2005: 287). Thus any experiences or views, such as the personal experience of impairment, that do not support the principles of the social model may be marginalised and ignored (Bury, 1996). Jenny Morris, one of the first disabled feminists, argues:

> The disability movement needs to take on the feminist principle that the personal is political, and in giving voice to such subjective experiences, assert the value of our lives. We can insist that society disabled us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our own oppression (Morris, 1991: 183).

The personal experience of impairment and gender are equally important to the social oppression and should not be excluded from the disability research (Morris, 1991; 1993). Morris in her later work further argues:

> There was a concern amongst some disabled women that the way our experience was being politicised didn't leave much room for acknowledging our experience of our bodies; that too often there wasn't room for talking about the experience of impairment, that a lot of us feel pressurised into just focusing on disability, just focusing on social barriers (Morris, 1996: 13).

Often the issues faced by disabled women were different from those faced by disabled men (Be, 2012) and thus women's experiences should be explored from a feminist epistemology (Stanley and Wise, 1990). Since the 1980s feminism played significant role in shaping disability studies (Thomas, 2007; Be, 2012). Morris and other disabled feminists advocate for the documentation of disabled people's experiences to develop shared understanding of what it is to be disabled. They refuse to make the distinction between 'the personal and the political' which is strongly utilised in the emancipatory paradigm which denies the reality of disability (Watson, 2000; Thomas, 2007). They applied the feminist slogan ‘the personal is political’ in researching disability (Morris, 1992) in opposition to the social model approach which focuses on the material, social and political, rather than the ‘personal experiences’ (Oliver, 1996; Finkelstein, 1996).

Feminists argue that disability studies should embrace the physical and emotional realities involved in living with impaired bodies which include pain, fear of dying, and coping with physical change (Morris, 1996; Wendell, 1996; Garland-Thomson, 1997). The feminists also place emphasis on ‘publishing research-based and biographical material detailing personal struggles with *both* impairment and disablism’ (Thomas, 2007: 125, emphasis in original). The feminist approach has made important contributions to disability studies which acknowledge that disabled people do not represent a homogenous social group (Shakespeare, 2006: Thomas, 2007) but rather that the experiences of disablism and living with impairment are intersected ‘with other cultural markers of social ‘difference’: gender, ‘race’, sexuality, age and class’ (Thomas, 2007: 70). These aspects of research are vital in understanding disability in the Global South which is made up of different dimensions of socio-cultural facet of disability experiences and identities.

As discussed in Chapter 2, disability is defined differently across cultures (Grech, 2009; Ingstad and Whyte, 1995; Coleridge, 2000) and thus requires specific cultural understanding of the disability phenomenon. For example in ancient cultures disability was directly observed as something related to sin and evil (Mackelprang and Salsgiver, 1999). As perceived in Indian society disability may be associated with bad karma (bad deeds) which were done in a present or a past life (Yamney and Greenwood, 2004; Vidya, 2011). Disabled women in India may also be subjected to greater social disadvantage as a result of the complex interaction between cultural belief, gender disparity and caste system (Mehrotra, 2008; Rao, 2010). They may be perceived negatively for being disabled, being a woman, and coming from lower class family. Jewish society also has distinct attitude towards disabled people in which many people with impairment and illness are considered as symbols of offence which accounted for them being exiled from the community (Barnes and Mercer, 2010: 15).

Researching disability thus requires careful attention to the complex interaction between different facets of a given culture or society.

So although, as argued earlier, the emancipatory research paradigms could be seen as a tool for disabled people's emancipation and empowerment in developing countries, there are increasing concerns over its utilisation in the local context (Grech, 2009:775; Turmusani, 2004:3). For which Turmusani argues:

> [...] the "emancipatory paradigm", which is the research machinery commonly used to explore the social model of disability, provides a limited tool for investigating disability concerns. Although, this approach emphasizes greater control of disabled people over the research process and its production, examples of disability policy research in Afghanistan where the author works proved it to be not universal. This limitation, it is argued, is due to its inherent theoretical limitation when focusing merely on political issues, especially in developing world contexts (Turmusani, 2004: 3).

In relation to this the emancipatory research paradigm located within the social model of disability may not provide a broader understanding into disability in the Global South; especially into disabled women's lives. Drawing from the feminist literatures and the works of Watson (2012a; b), Shakespeare (2006; 2014), Shakespeare and Watson (2001; 2010), that were built based on the writings of Bhaskar (1997) and other critical realists, the critical realist approach is seen as offering a wider perspective into researching disability in the Global South. Critical realism places emphasis on a non-reductionist perspective (Danermark and Gellerstedt, 2004; Bhaskar and Danermark, 2006) which focuses on both structural barriers to inclusion, and the individual agency that gives value to the different dimensions of disability experience (Shakespeare, 2006).

For example Watson (2012b) suggests that critical realism can be employed in childhood disability research to permit disabled children to actively contribute to the research plan by identifying what they see as being most important for them. It also allows for the collection of diverse social experiences of disabled children that includes 'social class, parental and family experiences, ethnicity and geographical location' (Watson, 2012b: 199) which is also suitable for application with respect to disabled women. The critical realist approach, as discussed in Chapter 2, allows for an exploration of different dimensions of disability experiences and for a different categorisation of disability because it is concerned with exploring how agency is influenced by structures and other factors (Watson, 2012a; b) and how they change over time (William, 1999). Following a critical realist approach, Bhaskar and Danermark (2006) thus argue that research into disability can be explored at different levels: physical, biological, psychological, psychosocial and emotional, socio-economic, cultural and normative; which are significant to the disability experience in the Global South.

Thus the feminist and critical realist approaches are seen as providing a valuable insight into the understanding of disabled women's lives in developing countries such as Malaysia. These two paradigms offer a wider understanding of the private and public life of Malaysian women with mobility impairment within the many aspects of Malaysian society; including the exploration of both the agency and structures. Therefore both approaches are fundamental in providing an alternative framework for disability research in the Global South as opposed to the emancipatory research paradigm.

3.2.2 Qualitative methodology and narrative research

This study employed a full qualitative research methodology in documenting the lived experience of Malaysian women with mobility impairments. 'Qualitative research embraces the view that as far as people's perceptions are concerned, there is no one single truth' (Hartley and Muhit, 2003: 103). This goes in line with the feminist research approaches that emphasise the pragmatic orientations, different national contexts and dynamic developments in women's experiences (Olesen, 2005). The qualitative approach 'reinstates' people at the centre of research agenda because it is used as a vehicle for collecting and analysing data based on the participants' world view (Muecke, 1997). Therefore, the qualitative research is important in understanding disability in the Global South (Stone and Priestly, 1996) and in particular the recognition of differences among women (Olesen, 2000).

In realisation of this the narrative research approach was used to undertake the qualitative research within this study. 'Narrative research is a form of inquiry in which the researcher studies the lives of individuals, through the collection of life stories usually by interviews. It provides a detailed picture of an individual's life' (Hartley and Muhit, 2003: 105). Narrative research can take different forms and this study employed the narratives as life stories (Jovchelovitch and Bauer, 2000; Creswell, 2007). This approach was chosen because the act of telling a story was fairly simple for the research participants. They were asked to tell their own stories in any way that made sense to them. 'By telling, people recall what has happened, put experience into consequence, find possible explanations for it, and play with the chain of events that shapes individual and social life' (Jovchelovitch and Bauer, 2000: 58). It also gives the participants a chance to make meaning from their experiences (even for 'painful' stories) and to share them and receive a response from their narratives (Dossa, 2006: 353).

This research approach was useful for gathering rich information about the lives of Malaysian women with mobility impairment. As discussed earlier the lack of proper documentation and research on the lives of disabled people in developing countries has meant this research approach provides a valuable insight to the understanding of disability in the Global South. Nevertheless the narrative approach is quite challenging as it requires extensive information collection regarding the participants and at the same time depends on a clear understanding of the participants' life contexts (Creswell, 2007). This refers to the multi-layered contexts of life that have to be uncovered where the researcher has to discover 'the figure under the carpet' (Edel, 1984 cited in Creswell, 2007). The narrative inquiry also requires active collaboration with the participants that is essential to this study. Such dynamic interaction as that which took place within the narrative research could empower the participants in generating their life stories and constructing the lived experience of Malaysian disabled women as a whole. Therefore this research approach allows for a dynamic understanding of the participants' lives.

3.3 Data Collection Methods

3.3.1 Ethical considerations

This research was conducted with great concern respecting ethical considerations to ensure the rights, privacy and wellbeing of the research participants were protected (Berg, 2009; Gibbs, 2011). I discuss this at the initial part of data collection methods to show that the ethical considerations framed the approach to this research. This study was conducted in a reflexive manner that integrated my thoughts and self-awareness throughout the research process (Etherington, 2004). ‘Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself’ (Finlay, 2002:532).

Prior to pursuing my doctoral studies I was trained as a counsellor and accredited as a registered counsellor by the Board of Counsellors Malaysia. My counselling skills and internship training as a counsellor to disabled students at a rehabilitation centre for disabled people in Malaysia has made me more aware of the ethical issues involved. Confidentiality and power relations issues became my main concerns to ensure that my participants were protected from physical and (psycho)emotional harm (Berg, 2009). As I am also a Malaysian woman with mobility impairment I had many points of commonality with the research participants. I found these facts were important and helpful in conducting this research as will be discussed throughout this chapter.

Before conducting the fieldwork, I obtained ethics approval in August 2011 from the ethics committees - College of Social Sciences, University of Glasgow. The fieldwork was then conducted from October 2011 to March 2012 (six months) in Malaysia. As the research was conducted in my home country, I was familiar with the local contexts in the aspects of diverse ethnic and cultural groups and religious beliefs. I provided each informant with participant information sheets (Appendix A) and an informed consent form (Appendix B), in both Malay and English versions, prior to the interview. Before conducting the interview I deliberately informed each informant about the general purposes of the study, the potential benefits and risks, and that their participation was voluntary: they could decide which questions they would answer or postpone, or they could withdraw entirely from the study at any time and for any reason. Written consent was obtained from each informant including their permission to digitally record the interviews, and they were each given a copy of the written consent for themselves. All data generated during the fieldwork, including digital recordings, field notes, transcripts and written consent forms, was kept confidential. The written consent forms were stored in a locked cabinet and all electronic data stored in both personal and office computers was secured and accessed with passwords that only I had access to it. All the participants' names were referred to using pseudonyms to protect their identity and to ensure anonymity. The informants' impairment, age and ethnicity were not identified unless it was necessary to contextualise their comments.

In conducting this research, I was aware of the nature of relationship that took place between my participants and I. It is argued the 'researcher-researched relationship' can create power imbalance between 'the subjects' and 'the researchers' (Watson, 2012a; Reynolds, 2002). Therefore it was vital for me to address this issue and take adequate interventions to overcome such consequences (discussed in 3.3.5). Also I was aware that a sense of sympathy and an impulse to help my informants might violate my position as researcher-interviewer (Lofland and Lofland, 1995). For example a participant in a sheltered employment informed that she was being abused financially by her warden and asked me to draw this issue to the attention of the administrators. Knowing that I was an 'outsider' to the organisation where she worked, and in my role as researcher-interviewer, I encountered an ethical dilemma. I discussed this with my supervisors and eventually I decided to employ an emancipation approach where I focused on her self-empowerment. I encouraged her to file a complaint with her organisation against the warden. In doing so I was able to empower her and at the same time I believed it did not violate my ethics as researcher-interviewer. This was one of the ethical issues arising from this study that needed to be considered conscientiously and led by sound ethical considerations.

3.3.2 Research participants and recruitment strategies

This study was conducted in three states of Peninsular Malaysia: Kuala Lumpur, Selangor and Negeri Sembilan. However the majority of informants formerly lived in other states in Malaysia; all over the country including states in Borneo, and most came from rural areas. 33 women with various forms of mobility impairments were recruited as my research participants: 21 with acquired impairments and 12 with congenital impairments. The sample included women with spinal cord injury, spinal muscular atrophy, poliomyelitis, muscular dystrophy, marfan syndrome, systemic lupus erythematosus, traumatic brain injury, gestational diabetes mellitus, osteosarcoma, spina bifida, teratoma, dysmelia, leg amputation and leg injury. Their age ranged from 21 to 57 years old across three main ethnic groups in Malaysia: 17 Malays, eight Chinese and eight Indians. The participants' recruitment roughly corresponded to the ethnicity ratio in Malaysia in which Malay is the dominant group, followed by Chinese and Indian. 19 were Muslims, six were Buddhist, five were Hindus and three were Christian. 23 of them were working while nine were not working and one was studying. In terms of relationship status, 14 were single, 18 were married or in a relationship, and one was a divorcee. All informants were interviewed twice except for five of them who were only interviewed once. Therefore the sample came from diverse backgrounds and provided rich data on their lived experiences.

The recruitment of my study took three different strategies – recruitment via: non-governmental organisations (NGOs) for disabled people, disabled friends' networking, and snowballing. The first strategy was with the assistance of six NGOs for disabled people in Malaysia (one of whom runs a sheltered employment scheme for disabled people). After I obtained the ethics approval from the University of Glasgow in August 2011, I contacted several NGOs by email while I was still in the UK. However, I did not receive any positive feedback from them. It was rather difficult to recruit the participants while I was not in my home country. Then I employed the second sampling strategy – disabled friends' networking. I contacted my disabled friends to assist me in finding their female disabled friends who would like to participate in the research. I provided them with the participant information sheets and informed consent forms to be distributed to their friends. I managed to receive about seven positive feedbacks from potential participants who were interested in taking part in the study. I then contacted them from the UK (via facebook, phone and email) and made initial arrangements to discuss the research when I returned to Malaysia in October 2011.

The recruitment process became much easier when I returned to Malaysia. Upon my return, I called the six NGOs and made appointments with them. They were more responsive when I met them in person and very happy to help me when they realised that I was a disabled woman too. I strongly emphasised to the NGOs that I did not wish them to use their power in recruiting their members as my research participants – it should be on a voluntarily basis. In the end I managed to recruit seven participants from one sheltered employment run by one NGO, and 11 from the other five NGOs. At the same time my disabled friends who did not participate in the research introduced me to their friends and I managed to recruit more participants from them.

The third sampling strategy - snowballing - was used after I conducted my first interview with the research participants. I asked them to introduce me to their friends who were willing to participate in my study. According to Biernacki and Waldorf (1981:141):

> The snowball method is well suited for a number of research purposes and is particularly applicable when the focus of study is on a sensitive issue, possibly concerning a relatively private matter, and thus requires the knowledge of insiders to locate people for study (1981:141).

I found this strategy was a more effective method for approaching the potential research participants because they were introduced by my own informants. Many were willing to take part in the study after they received positive feedback from my research participants on how I conducted the interviews. Moreover in many countries like Malaysia, where many disabled people are ‘hidden’ with no access through official channels, this approach works very well. However, it is worth mentioning that I had difficulty recruiting Chinese participants rather than Malay and Indian participants. Many Chinese women were reluctant to participate in my study because they thought that I was working with the DSW and the interview would affect the financial support that they received from the state. Also my inability to speak the Chinese language became a barrier since many of them could only understand their mother tongue. Despite these issues, I was able to recruit an equal number of Chinese and Indian participants especially through snowballing sampling technique.

3.3.3 Qualitative interviewing

To facilitate the narrative research approach, I employed a qualitative interviewing technique to gather the data. Qualitative interviewing is an 'in-depth, semi-structured or loosely structured form of interviewing' (Mason, 2004: 62). This study utilised semi-structured interviews with the informants to allow flexibility of the data being gathered in the interviews. The qualitative interviews were conducted based on the 'traveller metaphor' as suggested by Kvale (1996) in which the interviewer is seen as a traveller who journeys with the interviewee exploring the essence and meaning of the interviewee's lived stories (Ritchie and Lewis, 2003:139).

> The traveler [...] ask questions that lead the subjects to tell their own stories of the lived world, and converses with them in the original Latin meaning of conversation as 'wandering together with' (Kvale, 1996:4).

My background in counselling has developed my empathetic listening and understanding skills which assisted in the collection of the informants' lived stories. This created a 'wandering together with' them in their lives' journey. I appreciated every moment in the interviews as if it was my own stories and feelings. I will discuss this again in 3.3.5.

Before conducting the fieldwork, I decided to undertake a pilot study to have a 'clear definition of the focus of the study' (Frankland and Bloor, 1999: 154) and to 'identify potential practical problems in following the research procedure' (van Teijlingen and Hundley, 2001: 1). I interviewed two women from my disabled friends' network and their interviews also became part of the data. These two research participants came from different backgrounds, albeit both were Malay. The first informant came from rural area and later moved to a city. She was working with a private company and was still single. My second informant came from an urban area and lived in a city. She was working with a governmental agency, unmarried and 12 years older than the first. I conducted the interviews with ethical considerations and treated them as research participants.

The pilot interviews were conducted in safe and conducive settings but not in their home. Prior to the interview, I explained all the information written in the participant information sheets, their dual roles as a pilot and research participant, and attained their written consent. At the end of the interview I obtained their feedback on the flow of interview, suitability of questions asked, the interviewing skills and their feelings. Based on their comments, I made a few changes i.e. I had to provide them with leading questions to help them generate their narrative accounts. My initial intention was to engage less with the interview guide to give them more room 'telling' their own life stories. However, the pilot participants found that they did not know how to tell their stories if I did not direct them with leading questions. Therefore the attention given to 'how' their narratives were organised, and also to 'what' they said, were both important in understanding their lives' journey. The pilot interviews were conducted two times in line with the actual interviews which were conducted twice.

After I had completed the pilot interviews with the two women and made some adjustments following their feedback, I started to run the interviews from October 2011 to March 2012 in the participants' homes and NGO premises, and a few in the coffee shops (to maintain privacy they were conducted in secluded areas far from other customers and in less crowded shops). As mentioned earlier, each informant was interviewed twice and the time interval between the first and second interview was from three to six month. I used interview guides (Lofland and Lofland, 1995) for both the first and second interviews (see Appendix C and Appendix D). The first interview guide asked about the participants' backgrounds and lived experiences and revolved around several themes: impairment, family, gender, education and training, work and relationships. I found that the majority of participants did not have problem relating their lived stories and they were willing to share most of their significant life events albeit some were quite 'reserved' in telling their relationship experiences. At the end of the first interview I gave them the opportunity to ask me questions related to myself. This was important to make them feel that I was not superior to them and they could also learn about me just the way I learnt about them. The use of self-disclosure was encouraged by some feminist researchers to develop genuine relationship (Cotterrill, 1992) and thus create a non-hierarchical and non-manipulative research relationship (Berg, 2009). I also asked how they felt about being interviewed by me and how I could improve my interviewing techniques for the second interview. The first interviews lasted between one to three hours.

I listened to the recorded interview after each session and generated questions for the second interview. The second interview guide was more like a 'follow-up' session to the first interview to observe if the participants experienced changes in their lives over the gap period and to check on their emotional wellbeing after the first interview. Also I encouraged them to add bits to their story or to revise something which had been said previously. I came out with several themes that emerged from the first interview: social welfare, relationships, abuse experiences and their current feelings and life aspirations. The second interview was important to explore 'sensitive' issues that were not being told openly in the first interview e.g. relationships and abuse experiences. I found that the majority of informants were more 'open' in telling their private lives in the second interview, especially the Chinese participants who were less likely to 'open' themselves in the first interview. The two stages of interview were important to build rapport between my participants and I, as emphasised by the feminist approach (Berg, 2009). I managed to interview all informants twice except for five of them: four were unable to arrange for the second interview due to their work and family commitments (two of them emailed their responses on the second interview guide) and one refused to be interviewed for the second time. The second interviews took between 30 to 90 minutes.

Overall the two stages of interviews, with 33 informants and 61 interviews, were conducted over a period of six months in Malaysia.

3.3.4 Research diaries and field notes

I employed reflexive research diaries or logbooks to record my ideas, discussions with supervisors and fellow researchers, the research process, and anything else pertinent to the whole research and data analysis (Gibbs, 2011). I treated them as my personal documents that reflected my own 'journey' through the research. I used medium hardbound volume of research diaries that were essential at every stage of my research development. Research diaries are commonly used in the qualitative social research (Altrichter and Holly, 2005; Creswell, 2007). This method allowed me to be more reflexive (Etherington, 2004) concerning the research activities and served as 'external memory' to my own reflections.

Additionally I used field notes as part of the data collection method. Field notes are concurrent notes taken in the research setting (Angrosino, 2007) and during the interviews. The use of field notes during the interviews was quite different from my previous experience in counselling. As a counsellor I was trained to not make significant notes during the counselling session in order to maintain persistent eye contact with the clients. However in this research I found that taking notes during the interview encouraged the informants in 'telling' their stories easily because they felt that I was really interested in their points and making notes of them. It also reduced the level of eye contact between my participants and me that helped them to feel less embarrassed sharing their 'private' life stories. However this did not lessen my empathetic listening and understanding of them and appropriate eye contact was maintained throughout the interviews. At the same time I also wrote a reflexive analysis in the field before and after each interview (Finlay, 2002).

The research diaries and field notes were used both to facilitate my understanding of the research, and as data collection methods. They were used in a reflexive manner and helped me to be analytical regarding my roles as interviewer and researcher. They facilitated qualitative interviewing and maintained a good record of my personal thoughts, ideas and pertinent circumstances that influenced the whole research process.

3.3.5 Me and Them / I and We

As disclosed earlier, I share similar position to my participants – a Malaysian woman with mobility impairment - albeit we had some differences. Some feminist researchers outlined the importance of a reflexive sociology in which sociologists locate their own social identity and values within their work (Roberts 1990; Stanley and Wise 1993). Drawing on a feminist approach 'writing the self'

(Thomas, 1999) and biographical research ‘telling my own story’ (Roberts, 2002), I felt committed to locating my role in this research as a disabled Malaysian woman studying and reconstructing the lives of Malaysian disabled women. It is fundamental to provide readers with an insight into the subjective understandings and interpretations across the research from the initial design to the final write up. Also it is important to make visible my identity and reflect on how my personal story (e.g. impairment, gender, social class, ethnicity and religion) may influence this research at the personal and political level adhering to the feminist methodology on the principle of making the personal political (Morris, 1992).

Although my role as a researcher may have been perceived as that of an ‘insider’ to those participating in this research, at times I also had an ‘outsider’ position in some aspects of the participant’s life story. Both roles are important to the research as Dwyer and Buckel argue:

> Whether the researcher is an insider, sharing the characteristic, role, or experience under study with the participants, or an outsider to the commonality shared by participants, the personhood of the researcher, including her or his membership status in relation to those participating in the research, is an essential and ever-present aspect of the investigation (Dwyer and Buckel, 2009: 55).

As a Malaysian disabled woman, my informants and I shared the same societal stigma, prejudice and discrimination in our daily interactions with others. ‘Me’ and ‘them’ were always reminded that ‘we’ had mobility impairment through structural and attitudinal barriers in our society. Although the nature of impairment might vary, I had a similar onset of impairment as the majority of informants where we acquired our impairment at later life. We experienced a major life transition from being non-disabled to disabled and this significantly impacted on our identity formation and psycho-emotional wellbeing as disabled women. One of the informants, who had the same impairment episode, identified with me as we both had the experience of living with osteosarcoma (bone cancer), and as a consequence we both had leg amputation at the age of 16. Many other informants also made self-reference to me when identifying themselves with disability experiences although we had differences in our life outcomes. Such commonalities and differences helped me to locate myself within the research.

The majority of informants came from low income families and lived in rural areas but later moved to urban areas or their hometown underwent urbanisation: this was similar to my background. I was born to a low income family and raised in a rural area in the West of Peninsular Malaysia. My hometown underwent rapid urbanisation for the past 10 years, a few years after I acquired my impairment. Accessibility issues were paramount in my early years of living with disability whether it was at home, school or social settings – something that the majority of my informants and I had in common. When my informants told how their low economic background and geographic factors restricted their opportunity for accessible housing, healthcare, education, work and social activities, I could ‘wander together with’ them, not only because I employed empathetic listening, but also because I had experienced it myself. Most of the time, ‘I/we’ also faced social stigma, prejudice and discrimination from significant others and strangers in all life settings because of ‘my/our’ visible impairment. Such daily oppression and discrimination impacted on ‘my/our’ identity formation making ‘me/us’ more aware of ‘my/our’ disability identity. Reflecting on these subjective understandings, gave an important insight into the ontological world of my informants.

In terms of gender identity, my participants and I had similar exposure concerning how women were perceived and located within Malaysian society. Although I did not experience pertinent gender inequality within my family and society, at times my position as a daughter and as a woman was shadowed by male figures at the personal, familial and societal level. I was aware that women in Malaysia are always perceived as the home-maker, ‘weak’, and dependent on male characters, and as always needing protection (Koshal et al, 1998; Noraini, 1999; NGO Shadow Report Group, 2005; Aminah, 1998; Chattopadhyay, 1997; Azman and Juliana, 2005; Rohana, 1997). Therefore I realised that many Malaysian women themselves subscribed to such cultural conceptions within society and this facilitated my understanding of how gender influenced the participants’ personal accounts: especially in terms of exercising agency, physical appearance and relationships. It is worth mentioning that many participants were interested in knowing my marital status and many of them wished that I would get married soon to a good husband. Apparently, such dynamic interplay that took place between ‘me and them’ was influenced by our shared gender identity.

As mentioned in Chapter 1, Malaysia is a multiethnic and multi-religious society. The women interviewed were not a homogenous group: their diversities were discussed in 3.3.2. Locating myself within the Malaysian landscape, I belong to Malay ethnic group and am also a Muslim: these are features which I share with the majority of the informants. Although I am not Chinese or Indian, and I am a practicing Muslim, I was aware of the cultural and religious pluralism in Malaysia. I was raised in this cultural and religious diversity and never lived abroad until I pursued my doctorate degree when I was 27 years old. In some aspects, I realised that I was an ‘insider’ to Malay Muslim yet an ‘outsider’ to non-Malay Muslims. For example an Indian Muslim participant mentioned that she disliked Malay and hated Malay men. I was surprised and overwhelmed by such a statement at that time. However it did not affect our interviewing relationship because I applied the three essential conditions for effective counseling as proposed by Carl Rogers: unconditional positive regard, empathy and congruence (Rogers, 1957). In this respect, I accepted her feeling as true without any judgmental view; I explored the underlying issues behind her feeling (such hatred) and I was honest to her about my own ethnicity and my feeling of surprise over her statement. We managed to explore her feelings and lived experience in our first interview that lasted for three hours as she felt comfortable talking with me despite this issue. As a trained counselor I was equipped with cross-cultural understandings and skills, and as such it helped me to overcome the issue of being an ‘outsider’ in this research. It was important that such cultural and religious differences within Malaysian society were acknowledged and understood.

In addition, my religious identity was visible to all informants although I did not mention it to them unless they asked. As a Malaysian Muslim woman, my ethnicity and physical appearance informed them that I am a Muslim. For instance an Indian Hindu participant was aware of my religious identity when talking about her sexual experience as she said:

> We were intimate because I know I'm not going to get married. I mean like [you] because for Muslims of course that is not allowed. Not encouraged. I'm a Hindu. Yea, so it is [on] my conscience. It was between me and God. [...] I feel more complete. I mean having had a sexual experience and that means the joy of it.

Whilst knowing that my religious identity might prevent her from talking about her sexual experience openly, she felt comfortable discussing this with me despite our differences in religious practice. My ethnic and religious identities, which differ to the non-Malay Muslim women, was not a barrier to them sharing their private lives with me because for the majority of them my disability identity was more apparent: that made me an 'insider' to them. This dynamic interaction that resulted from our social divisions was important in increasing my awareness as both an 'insider' and 'outsider' within the research.

Although I share many commonalities with the majority of informants, there were some aspects that made me appear more 'advantaged' than them. I was aware that many of my informants had restricted opportunities in education and employment and consequently it hindered their full potential in society. Knowing my identity as a doctorate student (studying abroad), and having a job prospect with a public university in Malaysia, many informants expressed that they were not 'lucky' enough like me. I felt quite 'guilty' about this fact as I understood how they wished to be in my place. Although I also experienced similar disabling stories with the majority of them, many perceived that I had had better opportunities in education and employment prospects. Thus it made them feel that they were 'no better' than me. I acknowledged their 'upset' feeling and empowered them to have a positive life outlook despite their 'disadvantages'. I believe that such kind of interaction is important to empower the informants with the concept that disabled women like 'us' can 'be' who we want to be and 'do' what we want to do if 'we' were granted adequate supports and opportunities. I also acknowledged the possibility of power imbalance (relations) existing within such kinds of relationships. To overcome this, I employed several approaches: for instance I informed them that we are equal to each other (I was no better than them), they were helping me to understand the lives of Malaysian disabled women and that their contribution was essential to the development of social welfare policies and practices in Malaysia. In so doing indirectly I ‘told’ them that they were not ‘passive research subjects’. Indeed, many of them expressed that they felt happy that someone heard their ‘voice’ and it was good to talk about their lives with me.

3.4 Data Analysis and Interpretation

Qualitative data analysis involves both data handling and interpretation (Coffey and Atkinson, 1996; Flick, 2006; Mason, 2002). With that in mind, my analysis started in the field and involved several phases and levels of data handling and interpretation. The research diaries and field notes were used both to collect the data, and to begin the analysis. Flick (2006) argues that qualitative research is different because there is no separation of data collection and data analysis. It uses both inductive and deductive approaches to data interpretation. After each interview I made reflexive notes reflecting on the contents of the interview in general and on the quality of the interaction between my informant and me. This was important to allow me to make alterations to the interview guide and to improve my interviewing skills. Besides field notes and research diaries, the analysis process involved producing participants’ summaries, constructing transcripts, translating participants’ quotes, managing data through thematic coding and analysing narratives as this section will show.

3.4.1 Participant summaries

After interviewing each informant, I developed a brief summary of key features identified in the participant’s life story for both phases of interviews. This also included the participant’s biography describing their age, ethnicity, religious belief, location, impairment, marriage status, education and training and work experience. I used this summary to generate an abstract for each informant that framed my general understanding about them. Due to the quite large number of participants and interviews, this kind of brief description enabled me to ‘frame’ and ‘store’ individual pictures in my mind. Later it was also used to facilitate statistical analysis when group categorisation was needed and in particular reference to individual cases.

3.4.2 Constructing transcripts

The following phase of my analysis was transcribing all audio-recorded interviews. I decided to transcribe the interviews verbatim although it was time-consuming and laborious (Flick, 2006). The verbatim transcription refers to the process of reproducing verbal data including nonverbal cues (e.g. body language and silences) and emotional aspects (e.g. crying, sighs and coughs) into written text (MacLean et al., 2004; Poland, 1995). Whilst the verbatim transcription served as an exact replication of the audio-recorded words, Poland (1995: 292) asserts that 'the very notion of accuracy of transcription is problematic given the inter-subjective nature of human communication, and transcription as an interpretative activity'. Here my field notes were useful in facilitating the inaccuracy of transcription interpretation. The notes taken during the interviews helped me to understand the contexts when ambiguity occurred while transcribing the audio-recorded interviews.

I used two audio transcription software packages: Olympus DSS Player Pro Transcription Module and Transcriber. About 40 percent of my interviews were transcribed by using the Olympus software but it stopped working after I encountered a licensing issue. Then, I downloaded the Transriber software on the internet (freely) and used it for the remaining 60 percent of transcription. On a reflexive note, I found that the transcription demanded high level of physical and psycho-emotional competency. I not only experienced physical exhaustion but also psycho-emotional fatigue. During the transcription process, I was brought once again to a 'wandering together with' the informants which evoked heighten emotions that had occurred in the interviews. It reminded me of all psycho-emotional sufferings experienced by the informants that at the same time invoked my own experiences. This period was pivotal for me as I nearly gave up my research but later I managed to overcome the psycho-emotional outcomes that resulted from such 'traumatic' life stories. Indeed, my background in counselling really helped me to 'detach' myself from such 'emotional attachment'.

Besides constructing the transcripts I had a dilemma of when and how translation should take place within this study since the research findings should be presented in English. Given the fact that I conducted my research in Malaysia, the majority of my informants spoke in Malay (Malaysian) language and very few conversed in English. Working with translated transcriptions was difficult and might influence the interpretation process as argued by Riessman (2008). Conscious of this, I decided to not translate them all into English but left them in the original. I believed this method would allow me to stay closer to the data and to maintain the dynamic interactions that took place within the original 'voice'. Nevertheless the translation was only undertaken for selected quotes that were used in the written reports as discussed next.

3.4.3 Working from Malay into English

It is argued that very few researchers working in cross-language research address the translation issues and the role of interpreters/translators in presenting their empirical findings (Makita, 2012; Temple and Edwards, 2002; Temple and Young, 2004). For example in a study conducted by Nicolaisen (1995) on disabled people among Punan Bah ethnic group in Borneo Malaysia, the researcher did not outline how the translation process took place in the study. As a reader I was wondering about how and when the collected data was transcribed and translated into English as the findings were presented '[...] as if the interviewees were fluent English speakers' (Temple and Young, 2004: 163).

Undertaking a cross-language research, I was aware of the various possibilities and challanges of translation issues that might influence the interpretation of research findings and the research process itself. I believed that this translation issue should be addressed openly and in detail to preserve its methodological transparancy. As a native Malay speaker, I shared with my informants a similiar way of making sense of the world. In our conversations the Malay language was not just a tool or technical label that we used to convey meanings and concepts but it also incorporated values and beliefs within which we constructed our world. The language itself '[…] carries accumulated and particular cultural, social, and political meanings that cannot simply be read off through the process of translation, and organises and prepares the experience of its speakers' (Temple and Edwards, 2002: 5). Therefore, this section will illustrate how I dealt with the translation issues and how I positioned myself as a researcher-translator within the research.

Initially I was thinking of hiring a professional translator to translate the selected participants' quotes to be used in the written reports. Later I decided to do it by myself since I was the one who was physically and psycho-emotionally present during the interviews, listened to every single word from the informants, observed their body language and transcribed the audio-recorded interviews. I believed that I would be in a better position to translate the participants' excerpts since I was a native Malay speaker and English is my second language. As discussed earlier, I only translated the selected quotes that I believed best represented my informants' accounts, albeit incompletely. I decided not to translate every word in the transcripts into English because I did not want to lose the 'essence' of the informants' words within their original contexts and meanings. Also it would have been time consuming to translate them all. Here, it was crucial to choose which word 'represented' and 'communicated' best the view of my informants especially as it was represented in another language – English. Therefore, I ensured that the selection process was done attentively because meanings are constructed in, and not just expressed by, language (Barret, 1992).

Whilst I assumed that speaking the same language as my informants would help me to grasp the cultural context within which they constructed meanings and concepts, I was challenged with the difficulty of finding equivalent words in English that conveyed a similar meaning to that of the participants' words. To overcome this, I engaged in discussions with colleagues who were native English speakers and Malaysian friends who spoke fluent English. This strategy was useful in representing the participants' accounts to the best extent. I decided to preserve certain Malay words in the translated excerpts which I found useful to be kept in the texts. I also maintained certain language styles such as 'ma', 'lor', 'lah', 'aiya' that are typically used by many Malaysians especially Chinese and Indian when they converse in the Malay language or in languages other than their mother tongue. As mentioned earlier, few participants did the interviews in English and I purposely kept their styles of spoken English which were influenced by the local (Malaysian) styles. This would allow them to 'speak' for themselves without so much interpretation.

In this section I have presented some of the issues and dilemmas arising from working with data collected in non-English language. Although I have tried to reconstruct my participants' accounts to the best extent, it should be noted that the interpretations were influenced by my own views and English proficiency levels. Therefore the informants' account '[…] should not be considered as 'true' accounts but as selected and edited versions offering insight into personal lived processes' (Makita, 2012: 116). Before I proceed with the following section of how I managed my data to expand the analysis, here I present summaries for the process of knowledge production from Malay into English in Table 3.1:

Table 3.1 Working across Languages

Texts	***Description***
Interviews	Audio-recorded interviews were conducted in Malay (and a few in English)
Research diaries and field notes	Research diaries and field notes were generated in Malay and English
Participant summaries	Summaries and biographies were generated in English
Transcripts	Interviews were transcribed verbatim in the original language spoken (Malay and English)
Coding/categories	Codes and categories were generated in English
Informants' quotes	Extract examples were selected from the Malay interviews and translated into English (for English transcripts no translation was done)
Written reports	Analysis and interpretation of data was generated in English making use of the original Malay (and English) recordings together with the rest of the texts generated throughout the study

Source: Adapted from Table 3.1 in Makita (2012: 117)

3.4.4 Managing data

As mentioned earlier, I started my initial analysis during the fieldwork and throughout the transcription process in which the data collection and analysis were performed simultaneously. This was important to generate a reflexive understanding of my informants' accounts. Once I had completed the final versions of all the interview transcripts, and organised all the notes taken in the field, the analysis moved on to the next phase – constructing narrative and thematic analysis. This was done both manually and assisted by a computer program for qualitative data analysis known as QSR NVivo 9 (Bazeley, 2007; Creswell, 2007; Gibbs, 2011).

Before undertaking the use of QSR NVivo 9, I attended the Introduction to NVivo training course provided by the University of Glasgow IT services to acquaint myself with the software. The software was useful to store, manage and organise my data easily, especially the transcripts. First, I imported all the word-processed files into an NVivo 9 project: the participants' summaries and transcripts. I read all the transcripts on NVivo several times to familiarise myself with the structure and content of the participants' narratives: these included their life events, experiences, accounts, thoughts, beliefs and feelings. While reading through the transcripts, I identified key features such as the beginning, the middle and the end of each individual life story. This was integrated with the participant's summary and field notes that were prepared earlier.

After several readings of my transcripts, I developed a list of codes or categorisations by using free/tree node index system in NVivo. Some codes were merged into others, discarded or renamed after re-examining the transcripts, participants' summaries and field notes several times. This coding process allowed me to develop a thematic analysis that framed obvious and broad codes like 'childhood', 'healthcare', 'education', 'training', 'employment', 'family', 'structural barriers', 'attitudinal barriers', 'relationships', 'abuses', 'identity' and 'religion'. However, as I worked too close to the texts, I was aware of what Bazeley (2007) terms as 'the coding trap' that made me unable to see the big picture of the participants life story. Sometimes the coding process became too 'mechanistic' and made me 'lose the personal touch' for the narrative accounts and failed to locate individual biographies within broader structural, cultural and socioeconomic contexts. In fact the NVivo could serve as a tool to help me analyse the data, but it could not undertake the analysis for me (Weitzman, 2000).

Therefore I employed 'Labov's narrative elements' (see Gibbs, 2007: 69) in which it is suggested that a fully formed story has six elements: abstract, orientation, complicating action, evaluation, resolution and coda. It helped me to generate general understanding of the narrative, situate the participant's story in different times, places and situations, locate the sequence of events, evaluate the significance and meaning of life events, identify the outcome of events and to think about the participants' life transition. Such narrative analysis allowed me to move from simple coding and description to developing new ideas and ways of organising the material (Strauss and Corbin 1998; Roberts 2002). Thus I was able to identify various structural and cultural narratives of Malaysian women that intersected with their disability and gender experiences in broader and meaningful contexts within Malaysian society.

The analysis then identified four emergent themes from the empirical findings, namely: experiencing disablement; family relationships; love, marriage and motherhood; and identity constructions. The first analysis chapter on experiencing disablement was constructed based on both the participants' narrative accounts and the previous disability research in Malaysia. It was strongly influenced by the participants' socioeconomic conditions, geographical locations, impairment and gender that intersected with significant structural and attitudinal barriers within society. Many of the sub-themes were consistent with the previous empirical studies conducted in Malaysia (see Chapter 1) especially in the aspects of structural and attitudinal barriers in healthcare, transportation, education and training, employment and housing. However, the strong influence of culture, religion and gender were newly discovered and under explored in the previous studies. Therefore the first data chapter sets the background for the research that gives an initial understanding of how Malaysian women experiencing disablement in their lives.

The first substantial data therefore led to the next three data chapters that only emerged after the analysis. It observed how family played a vital role in the many aspects of the participants' lives. The second analysis chapter explores how family 'stood out' as a central primary care to the majority of the participants and how the dynamic of family interactions took place within the overarching influence of impairment, gender, socioeconomic, culture and religion. The complexity of Malaysian society therefore developed the third data chapter that observed the majority of women had dilemmas in pursuing their right to experience love, marriage and motherhood. This analysis chapter found that the majority of women had dealt with three levels of barriers in developing their personal (intimate) relationships with their partners that worked at the personal, familial and societal level. All empirical findings then framed an analysis for the final data chapter that examined how the participants constructed their identity within the complexity of Malaysian society. The majority of participants revealed how they were identified (or not) as 'disabled' in many different ways that informed their social interactions with others, impairments, gender, cultural and religious norms.The final analysis chapter thus frames the whole picture of how the women experience their lives living with impairment and disablement in Malaysia.

3.5 Conclusion

In this chapter I have presented the methodological framework of my study that details how I conducted the fieldwork and data analysis in a reflexive manner. I have discussed how disability research in the Global North influenced research into disability in the Global South. The two frameworks of research that I found useful in generating disabled women's lives in a developing country like Malaysia were feminism and critical realism as they explore disability experience from different aspects of lives. I also explained how the qualitative method and narrative research served as the most suitable tools of collecting women's lives experience of living with impairment and disablement in Malaysia.

I also described the methods used to collect the data through qualitative interviewing technique, research diaries and field notes. Special attention has been given to the ethical considerations throughout the research process to preserve my participants' rights and wellbeing, and at the same time to maintain my dual roles as researcher-interviewer. Although I had some difficulties in recruiting the participants across different ethnic groups, I managed to recruited significant numbers of them through disabled NGOs, disabled friends' networks and snowball sampling technique. On reflection my background as a certified counsellor, and also as a Malaysian woman with mobility impairment, helped me to generate the data reflexively and thoughtfully. I found that this study not only provided an understanding of my participants' lives experience living with impairment and disablement but it also made me aware of my own narrative accounts as a disabled woman in Malaysia and as a disabled researcher.

The data analysis and interpretation was also challenging as I had to remain focussed and attentive when constructing my transcripts and translating my participants' quotes into English. Working in cross-language/cultural research was undeniably demanding yet significant. Therefore emphasis was given to how I managed the data conscientiously to represent the best picture of my participants' lives without 'bracketing out' any fundamental narrative accounts.

Indeed this is not my participants' lives stories alone but this is 'our stories' that we shared together in a meaningful life journey. The following data chapter thus explores how women with mobility impairment experience disablement in Malaysia.

Chapter 4: Experiencing Disablement

4.1 Introduction

This opening data chapter sets out an introduction to a number of significant issues underlying the lives of the majority of women interviewed regarding their experience of disablement. This chapter will highlight two main themes that played vital roles in shaping the women's experiences of disability: poverty and rurality. It was observed that these issues had become primary causes of disablement for the majority of women interviewed. As suggested by Trani et al. and Groce et al. (in Groce et al., 2001: 4-5), disabled individuals with both congenital or acquired impairment often face social marginalisation and have limited access to healthcare, education or employment; leading them to poverty which later restricted their access to safe housing, food and so forth.

In this chapter the systematic impact of poverty and rurality upon women's lives will be discussed in six areas: healthcare, transportation, education and training, employment, housing, and family life. In addition structural barriers and societal disabling attitudes towards the women in this study also contributed to their disablement experiences. All these aspects will be discussed throughout this chapter.

Before discussing the themes the chapter starts with an overview of the socio-historical backgrounds of these women. On average the age range of the women interviewed was from 21 to 57 years old. The youngest woman was born 34 years after Malaysia obtained its independence in 1957 and the oldest was born just two years after independence. Since independence Malaysia has gradually developed in socio-economic terms and has moved from being a predominantly agricultural economy to an industrial economy (Hasnah et al., 2011) and a knowledge-based economy (Noor Masayu et al., 2012). The majority of the women, especially the older ones who were born in the early years after independence, had previously lived in villages and rural areas. They were born to low-income families and many of them lived in poverty. This trend occurred across all ethnic groups.

Of the 33 women, the majority of them (28) were born and raised in rural areas. Of the 17 participants of Malay ethnicity, 15 came from villages, estates or rural areas; whereas seven out of the eight of the Chinese interviewees formerly lived in rural areas and six out of the eight Indian participants lived in estates or rural areas. People from the rural communities in Malaysia tend to have limited access to information, facilities and developments compared to those living in big cities. The majority of the women later moved to urban areas; a trend that is reflected in the rest of the Malaysian community as since 1957 the country has been undergoing rapid population migration from rural regions to urban centres (Tarmiji et al., 2012). This matched broader demographic patterns. For instance, in 1950 only about 20 percent of the country's total population lived in urban areas: this had risen dramatically to 71 percent by 2010 (Department of Statistics Malaysia, 2011). The majority of the participants grew up in low socio-economic conditions which hindered their opportunity to access adequate healthcare, accessible transportation, education and training, employment and housing. This first substantial data chapter thus explores how the participants experienced these areas, the effects they had on their lives and on their ability to be included.

4.2 Healthcare

Since its independence from Britain 56 years ago, Malaysia has gradually improved its healthcare system and now medical care is dominated by western biomedicine (Kamil and Khoo, 2006). A detailed discussion on this is set out in Chapter 1. Traditional medicine is also widely practised by much of the population (Ministry of Health, 2005; Kuno, 2007). This section will examine how the interviewees experienced their lives in terms of healthcare within the socio-cultural contexts of Malaysian society.

4.2.1 Access to modern medicine

Access to modern (western) healthcare was difficult for many of the participants. There were many causes of this, including finance, geography and poor transport. For example Jiaying described how her family's poverty prevented her from getting modern medical treatment:

> From what I learned from my mother, I got Polio because of a high fever. I was about one year old at that time. My mother had very little money because she was only a rubber tapper. My father was a carpenter. Our life was so hard at that time because I had many brothers and sisters. I have 14 siblings […]. So when they knew that I fell sick, they took me to see a Buddhist monk. They never took me to see doctors but they always took me to pray […]

Finance was not the only barrier to accessing modern healthcare among the participants; geography was another factor, as described by Farah who lived in a village and had limited transportation:

> **Me:** So this means you never went to hospital? Is it that X [her village area] is a rural area that is far from a hospital?
>
> **Farah:** It's quite far. My mother is poor. We were using a bicycle to travel from one place to another […] That's why we never thought to go to the hospital; never going for any treatment […] I went to see a doctor at the vocational centre for disabled people while I was studying there.
>
> **Me:** That was your first time seeing a doctor?
>
> **Farah:** Yes. When I attended school, there were no doctors […] When I studied at the centre [for disabled people], I went to X hospital. The doctor said that I had Muscular Dystrophy – like a muscle problem; the bone is getting weaker day by day. I was so upset [...]

In the early years after independence, the Malaysian healthcare system was predominantly focused on catering for the needs of people in urban areas rather than those in rural communities (Chen, 1981 cited in Kamil and Teng, 2002: 99). 'Rural health services were largely non-existent and, if available, were based in health centres located in small country towns' (Kamil and Teng, 2002: 99). Therefore people in rural areas had limited access to the healthcare services provided by the state. This was confirmed by many of the women interviewed who lived far from the city.

The absence of healthcare services in rural areas, and the high incidence of poverty meant that many women were brought by their families to receive traditional treatments from local traditional healers. As Ika described:

> **Ika:** When I was 2 years old, my bone was not bending – it was normal. Then when I was in standard 1 [seven years old], it started to bend.

> **Me:** When it started bending, did you see a doctor?
>
> **Ika:** No, never. I just went to traditional massage – my mother took me to have a normal massage.
>
> **Me:** Oh, so that means you have never been into a hospital?
>
> **Ika:** No.

Consequently many of the rurally-located women interviewed obtained traditional rather than modern medical treatments, due to the difficulties of accessing modern healthcare. Therefore the remedies available to them tended to be the ones offered by the local traditional healers, shamans or religious person. It would however be wrong to claim that participants only turned to traditional medicine because they could not access western medicine, the use of traditional medicine was widespread amongst all the participants and it was clear that the majority of them, regardless of age, ethnicity, class or location, had obtained some form of traditional treatment at least once in their lifetime, often by choice. This suggests a pervasive cultural influence in their healthcare experience, which this chapter will now turn to.

4.2.2 The role of traditional medicine

In the section above, in explaining their choice of pursuing traditional medical treatments, the participants expressed that it was primarily driven by their economic background (poverty) and their location (rurality). Nevertheless, regardless of background, the majority of the participants had sought traditional treatments at least once. This suggests a greater cultural influence than that of just economics and geography.

For example a Malay woman Yasmin, who came from a rural area, mentioned that her family brought her to seek various traditional treatments instead of modern medical medicine because they had little faith in the hospital:

> When I was in my hometown, my family took me to seek traditional treatments from many traditional healers. You know, villagers don't really have faith in the hospital. They thought my condition had resulted from evil spirits.

Many families believed that their daughters' impairment resulted from demonic possession or evil spirits as described by the two women below, on Hindu and the other Muslim:

> I have tried many traditional treatments since I was small. I think the last time was 10 years ago. That Hindu monk said that I was possessed by an evil spirit, so he asked me to stay in his place for two weeks (Prema, Hindu).
>
> I went to see a religious person. He said it had something to do with an evil spirit. So he used Quranic verses to treat me. He asked me to recite some verses frequently (Nora, Muslim).

These common cultural beliefs and a tendency to seek help from the traditional healers or religious persons were evident across different ethnic groups (religions) and socio-locations. It therefore indicated that there were significant cultural and religious influences in meeting the need for a cure amongst the participants. As Kamil and Teng argue:

> Despite the wide availability of modern scientific healthcare services that are accessible to Malaysia's rural and remote populations, traditional healthcare services are still used by Malaysian communities for a variety of health and psychosocial problems (Kamil and Teng, 2002:102)

For example Cuifen, who lived in a city and acquired her impairment at age seven talked about the role of traditional medicine in her life:

> No matter whether it was Indian, Malay or Chinese, we went to them all. Whenever my father heard about any good traditional healer, he took me there. He wanted me to be cured. But, it didn't work.

The actions of Cuifen's family, with their strong reliance on traditional medicine, were driven by the quest for cure. People were not interested in the type of healthcare or in its origin; all they wanted was a cure. This cultural representation of healing is complex and should be understood from different ontological levels: biomedical and psychological intervention (see Shakespeare, 2006: 112-117). Disability in Malaysian culture, as in most other cultures, is generally seen as a negative attribute that people do not want to be associated with (see chapter 7). Many women and their families were culturally informed that having an impairment was defective and actions should be taken to eliminate it. However, modern medicine ‘failed’ to cure these women and consequently they turned to traditional remedies. This caused significant psycho-emotional damage to these women as they grew up, reminding them that they were seen as ‘not perfect’ and ‘different’. Moreover they were influenced by their cultural and religious beliefs that created a self-perception that their impairment might be linked to demonic possessions or evil spirits and must be treated. ‘Among Malaysians, and especially the Malays, the traditional belief that spiritual forces play a great role over physical and mental health is dominant’ (Haque and Masuan, 2002: 277). Thus we can see that disablement was not just about economic and geography, but was also culturally reinforced.

This strong cultural belief and common practice did not only impact on them psycho-emotionally but they were also subjected to financial and sexual exploitation by the traditional healers. Several women revealed that they had spent lots of money on their traditional treatments and on many occasions they were cheated by the traditional healers. For example, as mentioned earlier, Yasmin recounted that her family had little faith in modern medical treatment and this had led them to be financially exploited:

> They [her family] thought my condition had resulted from evil spirits. So we went to many places and some of them cheated us out of our money. Then, a few years back [more than 20 years after she became disabled] I lost RM400 to a married couple. They guaranteed that they could cure my paralysis [...]. They convinced me that they could help me to walk again. When I heard them say that, I was so delighted. Because I desperately wanted to walk again, I paid them RM400 that night […]. I fell asleep when the wife massaged me. When I awoke, I saw no one and my money was gone.

Because of their strong belief in traditional treatments and their enthusiasm to get a cure, Yasmin and her family did not only experience financial loss, but also psycho-emotional distress resulting from the exploitation. Hope of a cure could also be linked to the earlier point regarding making them feel ‘different’ and defective. This form of financial exploitation by traditional healers was also experienced by many of the other women interviewed. Furthermore several of the women described how they were not only exploited financially but subjected to sexual exploitation by their traditional healers - often by respected men in their village and their family's friends.

Ainul described how she was traumatised when her private parts were touched by her traditional healer without her consent:

> **Me:** So it means he massaged your private parts? Where, your vagina or your breasts?
>
> **Ainul:** The vagina. When he touched it I felt scared. Then I tried to avoid him whenever he came to my parents' house [...]. When I thought about the incident, I felt scared. I had a spinal injury and I don't feel anything from the waist to the bottom of my body. I was scared of not realising that people were taking advantage on me.

She felt all the more under pressure because of her parent's belief; the traditional healer was a respected man in her village and a family friend. Therefore, she was reluctant to inform her parents of the incidents as she felt that they would not believe her and this could create tension over their relationship with that man. As a result she kept it to herself and this caused intense emotional impact over her bodily experience.

Similarly Nadia was also subjected to sexual harassment by a traditional healer who also happened to be her family's friend:

> The man touched my body. I was stressed at that time as I asked him to massage my arm but he massaged my legs. I said to him that my arm was painful so why massage my leg? [...] He said this is the proper way of massaging. Then after the first massage I told my mother that I didn't want to go anymore for the next session [...] He was taking advantage of me. But I did not tell my father because that was one of my father's friends.

The close relationship between the traditional healers and the families of these women had prevented them from exposing such incidents to their family and seeking justice. This was reinforced by the collective nature of Asian society which values religious figures and those in higher authority. Yasmin, as discussed earlier, also confided that she had nearly been raped by a well-known shaman in her village:

> I was nearly raped by a shaman in my hometown. I was given a medicine and felt asleep. Then the man asked my father to wait outside the room. When we were alone in the room, he switched off the light. Fortunately, my father secretly watched through the holes of the room. When he saw the man tried to rape me, he rushed into the room and saved me.

Despite the seriousness of this incident and her father's awareness of it, they did not report the sexual assault to the police. This was because the sexual perpetrator was her family's friend and therefore the incident remained secret. She has remained traumatised by the incident and has never received justice for herself. Indeed of the 33 women interviewed, five of them confirmed they had experienced sexual assaults from their traditional healers and none of them reported it to the local authority. This can be regarded as a cultural constraint where the Malaysian culture was embedded in these women to such a degree that they were unable to challenge the respect given to religious figures and those in higher authority within their local area. As a result, this cultural influence led to significant physical and psychological damage to these women.

Nonetheless, many of the women interviewed were not only subjected to sexual exploitation in traditional treatments but also in modern medical treatments; as will be described next.

4.2.3 Malpractice in modern healthcare settings

The previous section described how many of the participants were subjected to financial and sexual exploitation from traditional healers. Such mistreatment not only occurred in the traditional settings but also in western bio-medical settings. Discussion here explores the frequency of mistreatment in healthcare amongst the women interviewed and the type of abuse. This ranged from sexual abuse and inaccurate diagnosis, to inadequate treatment and misconduct on the part of their physicians.

First, the discussion begins with incidents of sexual abuse in modern healthcare settings. Three women described how they were sexually abused by their healthcare professionals. Eryna, for example, told of how she was traumatised by the sexual abuse experienced in her early impairment:

> [...] Then it happened in the hospital. It was my first time going to the X Hospital. Before I was referred to a specialist, I was checked by a medical doctor. He took off my clothes, everything including my underwear […] I don’t know what he was trying to check by doing that. But it shouldn’t be [like that] as it has nothing to do with my leg […] He took advantage as I was only 14 years old at that time. Why did he want to take off my underwear right? It wasn’t right. It happened once before when I went to see a specialist […] I didn’t tell my family, I just kept it to myself.

As had occurred in the traditional settings, Eryna was also prevented from expressing her concerns over her physician’s misconduct towards her as she felt that he was superior to her. By contrast Wei Yin strongly objected to what she perceived as inappropriate treatment undertaken by her physician:

> **Wei Yin:** When I was in standard 1 or 2 [seven years old], my father brought me to see a doctor in the X Hospital […] During our second or third meeting, the doctor asked me to take off all my clothes. I am a girl right and I felt embarrassed. I refused but my father convinced me to follow the doctor’s will […]
>
> **Me:** Although he did not do anything in front of your father, you felt…
>
> **Wei Yin:** Oppressed!
>
> **Me:** Yes you felt oppressed…
>
> **Wei Yin:** At that time I felt humiliated you know. It was just like my dignity as a human being was gone. Although my father protected me, he could not object to his order at that time. Why did my father follow his will? Is that because he was a doctor? Because he was highly educated? I felt it was unfair to me! This is unfair to me I said!

Although Wei Yin had exercised her agency by expressing her objections, she remained helpless because she was overshadowed by a significant male figure in her life – her father. Such an unforgettable incident created tension in her and it made her feel oppressed and vulnerable, even 40 years later. Since that incident, she refused to continue her medical treatment and never wanted to go to the hospital again. Therefore the sexual abuse experienced by these women in healthcare settings, both in traditional or modern medical healthcare, significantly impacted upon them over time and violated their dignity as women. It did not only ‘bruise’ their physical and psychological persona but it prevented them from getting appropriate healthcare services too.

It is important to point out that these are not uncommon experiences for disabled women everywhere. As McFarlane et al. (2001) have argued disabled women with physical impairments ‘are more likely to experience physical or sexual abuse by attendants and healthcare providers’. Young et al. (1997: 43) likewise found that ‘women with physical disabilities also were more likely to be abused by their attendants and by healthcare providers’. This lack of power appears to be an almost universal characteristic for disabled women and a unifying feature of the female disabled experience.

In addition to the sexual abuse experienced by some women in modern medical settings, other women received a wrong diagnosis by their physicians and as a consequence did not receive the appropriate healthcare. As Amanda Chan described:

> Then I met with an accident on the day when I was helping my parents on a farm in X (a state in Borneo Malaysia). So I had spinal cord injuries, but due to the ignorance of the doctors and all of the medical personnel there, they said it was alright because I had no external injuries [...] They gave me two painkillers, very painful, two injections to kill the pain. And then, I allowed my father to carry me up here and down, you know. That is where I further injured my cords; spinal cords. This resulted in me being a complete paraplegic. I’ve lost sensation and can’t control my bowels and my urinary functions.

Amanda Chan came from poor family who lived in a very remote area (a state in Borneo Malaysia which is less developed than Peninsular Malaysia) with limited healthcare facilities. She had to rely on local healthcare services as she was restricted by her remote location and financial constraints and could not access a better healthcare service in a big city or in a private practice. Therefore the poor services she received from the local government hospital resulted in her acquiring a permanent impairment.

Mistreatment in government hospitals was also common in the 1960s, as described by another woman:

> My bones were very soft when I was a baby. The doctors did not know how to push my bone properly and as a result my bone was dislocated [...] After I grew up, the X-Ray showed that my left leg was shorter than my right leg. They wanted to do an operation to put it back but it was useless (Alice Chong).

Some women were also frustrated with what they saw as unethical practice. This mostly related to a lack of control over the medical encounter where the health service professional failed to take account of their views and perspectives. For example, Murni explained how she felt uncomfortable in a healthcare setting:

> Usually, the doctors liked to bring their interns. Internships – they liked to thoroughly check us and sometimes I made a joke about it […] maybe that's free medical advice but I made a joke a little bit *lah*[10] sarcastic joke *haa* 'you watch a show?' I don't like you know erm... I don't go and chase out *lah* [she did not show her anger to them despite feeling angry] [...] it's up to the doctor right, because you don't know right […] I felt uncomfortable actually

Although Murni was an educated woman who believed she should have had more say over her rights, she still felt that her physicians had greater autonomy over her body. It disempowered her and made her feel inferior and she felt unable to let them know how she felt.

Likewise, this made Ika decide to discontinue her medical treatments:

> They liked to study me. When I went to the hospital, they took everything, like my blood, all they wanted. Lastly, I did not go there again after they wanted to take my bone sample. I asked my family and they advised me not to allow them to do that […] They actually wanted to treat me as an experimental tool […] They said they never met a patient like me, that's why they were really interested in me, especially the medical students.

The above examples highlight the imbalance of power between the research participants and their physicians, again a situation prevailing in other parts of the world, as Lundgren et al. (2004) have demonstrated, 'it is the power-imbalance between professional and patient that allows healthcare professionals to exploit or abuse as well as to heal'. Such types of exploitation made these women develop negative attitudes towards medical practice. Consequently, it prevented them from getting adequate medical advices and services, resulting in an intensification of their impairment and disablement experiences.

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[10] *Lah, lor or ma* are additional words (added at the end of any sentence) typically used by many Malaysians especially Chinese and Indian when they converse in the Malay language or in languages other than their mother tongue.

In brief, getting access to adequate healthcare was not a simple issue for many of the women interviewed. It involved a complex interaction between economic, geography, traditional/cultural beliefs, malpractice in the healthcare settings, and gender issues that hindered their opportunities for adequate healthcare. Now the discussion moves on to the barriers in transportation experienced by the majority of participants.

4.3 Transportation

Many of the women interviewed revealed that they had experienced significant barriers in getting access to the public transports where they had to deal with the issues of inaccessibility and negative attitudes of the public transport providers. This section will discuss how these barriers excluded the women from wider participation in society and how this impacted on their psycho-emotional wellbeing.

4.3.1 Access to public transport

Access to public transport, including buses, trains, and taxis, was for many women difficult. Most of them experienced significant mental distress when trying to overcome the structural barriers pertinent to transport. This exacerbated their psycho-emotional wellbeing and amplified their disablement experiences.

In Malaysia the private vehicle (car) has become an important and dominant mode of transport due to the inadequacies of the public transport system (Amin, 2009; Abdullah et al., 2007). There is also a well-developed ‘car culture’ where an increase in car ownership has been driven by rising incomes (Jamilah and Amin, 2007) and resulted in a public sector-led work project to build highways, as well as a domestically subsidised automobile industry, especially prevalent in Peninsular Malaysia. The focus on encouraging domestic car ownership has led to a poorly integrated public transportation system, despite such colonial legacies such as an extensive rail network system. On the other hand, the cost of owning a car remains exorbitant to many, leaving them to sign up to bank loans in order to buy a car which has now become a necessity not a luxury. Such financing options however remained out of reach for those in the lower classes, the unemployed, and those on welfare. For the majority of women interviewed their low economic status prevented them from owning their own vehicle and as such it made them dependent on public transport. The transportation scheme or assistance from the welfare state for disabled people was also inadequate. Although the government provided road tax exemption and a 50 percent discount of excise duty for vehicles of those with a physical impairment (see Chapter 1, 1.3.2), this was only applicable to those who could afford to buy a vehicle in the first place. For those with lower income or unemployed, buying a car was not an affordable option and thus it made them highly dependent on public transport.

Therefore buses remained the cheapest form of public transportation, and a necessary one for many if they wanted to remain included in mainstream life. However for many women with mobility impairments taking the bus was not a simple matter. As Nani described:

> I think my major obstacle was using buses. For example, buses on campus were not accessible for disabled people. So when they don't provide accessible transportation for disabled students, especially those who use wheelchairs, then it's very difficult. Like for me, if I wanted to go anywhere, I had to take taxis because I couldn't rely on buses […] it's difficult for a student like me because I have little money [to hire taxi].

The inaccessibility issue was not only apparent for short-distance buses but also for longer-distances as Prema mentioned:

> I could only go back home to my parents' house every six months. It was more difficult if I wanted to go back to my husband's hometown because we had to take a bus for like nine hours. Oh! If I took the bus, I couldn't eat, couldn't urinate, and couldn't go to the toilet. I didn't even eat for the whole day when I went back for Deepavali [a Hindu festival]. Sometimes I thought that it would be easier if we had a car so that we wouldn't have to suffer like that.

Although Malaysia has an extensive train network, the system is rather poorly maintained and integrated due to a funding deficit and a lack of supportive policies (Amin, 2009). Trains too posed obstacles for the participants – especially those in wheelchair as Yana described:

> You know what, I used to take trains when I wanted to go back home during the long term holiday. I like taking the train because it is more convenient than the bus because with the bus, I can’t even take the steps. But still taking trains was difficult too. It was really difficult because the train’s doors that lead to the passengers seats are too small for my wheelchair. My wheelchair is big and the door is too small […]. They asked me to walk to the seat but I couldn’t. Because of that they put me at an empty space at the entrance door. But it was not safe. There was one time, the door suddenly opened when the train was moving. I was shocked! I screamed and asked them to close the door. Then they came and fixed the door. But it was traumatic, you know. It was not safe at all! I paid for my seat but I couldn’t even use it and I was put just in front of the train’s door. I felt upset to be treated like that as if I am not worth taking the train.

The inaccessibility of the public rail system was not only experienced in the rail compartment itself but also at the rail station as explained by Fatin, also a wheelchair user:

> It depends on which rail station I take. Like for instance in X, it was fine because they had lifts. But in some other places it was not. They didn’t have lifts and I needed to take a number of steps in order to go to the platform. So, it was really difficult […]. Every time I needed to go out I had to think of all the possibilities of whether the station was accessible or not for me. It’s very frustrating.

Clearly negotiating the public transport system was not a simple issue for these women. The structural barriers significantly impacted upon them not just physically but also psycho-emotionally. It affected their ability to keep in contact with family members and friends; a problem that was for many intensified as they were often forced to live a long distance away from their family home for accessible education, training or employment. Consequently, they were marginalised and denied equal access to wider economic and social participation. As Stephanie Thomas a disabled activist and an organiser with ADAPT[11] asserts:

> It is not coincidence that transportation was such a tinderbox issue. Transportation, both symbolically and in reality, is the key to linking with others. Mobility, the ability to get out, to get around and connect

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[11] ADAPT is community organisation based in Washington, DC that organises disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of disabled people to live in freedom (ADAPT, 2014)

> with other people, is fundamental to being a part of a larger community (Thomas, 2001: viii).

4.3.2 Disabling attitudes and discrimination in accessing public transport

Whilst public transport became an important option for many of the participants with low incomes, many had difficulty in accessing public buses and trains. As such they often found that using taxis was more convenient for their physical limitations especially for those in wheelchair. However in using them, they were often subjected to attitudinal barriers, including discrimination from the drivers.

Yana described her constant frustration in getting taxi services:

> Many taxi drivers will not take us if we ask unless we call them first. Even at the supermarket where many taxis are there, waiting for passengers, they hardly ever want to take me with my wheelchair. They say that it's difficult to put my wheelchair in the taxi's bonnet as they use gas. Sometimes they say it will make their taxi dirty, or that my destination is too far for them, or there is a traffic jam – and many more excuses. Then on one occasion, a taxi driver refused to take me as he said now the traffic is too heavy. But two minutes later, I saw that he took a passenger although he said it was heavy traffic at the moment. I felt it was unfair to me as he could take other people but not me?

Such an incident was typical of the experiences of many of the women in wheelchairs and reflected wider attitudinal and structural discrimination. Although the DSW introduced the PWDA 2008 that included equal access to transportation, disabled people are remained discriminated against through the public transport system. Many commentators believe that this is largely because the act does not carry any penalty and it is reliant on the goodwill of the public to conform (Jayasooria, 2000; Kuno, 2007).

Yasmin further described:

> I have always had problems when getting a taxi. When I stopped them, they said that they didn't want to take me […]. Some of them said that 'taxi drivers can't lift the wheelchair' […] Then I told him if he wanted to charge me extra because of that, I was fine with that. This was because I had stopped many taxis but none of them wanted to take me, even though the taxis were empty […]. Only then he was willing to

> take me. Then, on many occasions, they charged me extra because they had to lift my wheelchair into the car.

Prema, another wheelchair user also shared:

> If you are rich, you can get all the maids and everybody to look after you. You don't feel the pain. You don't feel anything. Like people like us, we can't, you know, we, you call for a taxi, you know how much it is? Taxis don't want to take you. Sometimes you have to argue with them [...]. They don't want to have the difficulty of taking a person on a wheelchair. It's public transport. So we want, you know, taxis that are accessible to us.

This problem of gaining access to all types of public transport, including taxis, has been largely reported by those participants who were wheelchair users. These findings were similar to the previous findings on access to public transport for disabled people in Malaysia as discussed in Chapter 1. Hence many of the women interviewed were not only prevented from equal access to transportation but also to education and training as will be discussed next.

4.4 Education and training

This section examines barriers to education and training. Before doing this the educational background of the participants should be stated. Of the 33 women, the majority attended formal schooling provided by the state, with 14 of them completing secondary (high) school and sitting the Malaysian Certificate of Education (*Sijil Pelajaran Malaysia - SPM*[12]). Eight of them sat the Lower Secondary Assessment (*Penilaian Menengah Rendah* - PMR) but did not complete secondary school; while two of them completed primary school and sat the Primary School Evaluation Test (*Ujian Penilaian Sekolah Rendah* – UPSR), yet they did not proceed to secondary school. Two women never attended formal schooling; they learnt to read and write informally at home. However only seven women managed to complete secondary school and progressed to higher education to study a diploma, degree, masters or doctorate of philosophy (PhD). This contradicts with the general pattern of educational attainment amongst female population in Malaysia. According to the 2010 Census almost 68.9 percent females aged 15 years and above obtained a tertiary education; as compared to

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[12] SPM is equivalent to the British O-Levels and is crucial as it is used as a baseline to apply for higher (tertiary) education and also for employment in Malaysia.

males who were only about 66.8 percent (Department of Statistics Malaysia, 2011). It indicates that the majority of participants achieved a lower academic level than the rest of the Malaysian females' population. Therefore this section will show how many of the women interviewed encountered significant obstacles in their education and training experiences in terms of structural barriers, attitudinal barriers, and limited opportunities for training.

4.4.1 Structural barriers to education

As revealed in Chapter 1, for many of the women, especially those in wheelchairs, structural barriers at school became a major obstacle to their continuing within education. For example, Fatin, a wheelchair user, explained that she had to quit school because her school failed to provide an accessible classroom for her:

> After I recovered from the accident, I wanted to continue my studies at secondary school. Unfortunately, I couldn't register to form 1 [equal to Year 8 in British secondary education] because all the classrooms were located on the upper floor. So, I couldn't take my PMR at school and I took it as a private candidate […] After PMR I didn't take SPM because it was hard to study alone at home.

Similarly Lijuan also experienced similar environmental barriers at school. She not only encountered inaccessible school buildings but also was unable to find suitable transport to the school due to her impairment and poverty:

> I didn't go to school after standard 6. There were a few steps in my school which I couldn't take *ma*. Although the school's buildings were all single storey, there were a few steps in the buildings. So I couldn't go and my mum also didn't have time as she had to look after my siblings *lor*. I also couldn't get onto the school bus because it had a few steps at the door. It was really difficult […] I felt upset that I couldn't go to school *lor*. I liked going to school, it was fun, but I couldn't do it.

Lijuan's family could not provide a car or assistance for her getting to her school because they were poor and apparently neither the state nor school provided adequate support for her. The inaccessibility of Fatin and Lijuan's schools had prevented them from having an equal opportunity to gain an education and as a result both of them had to quit school earlier than they wished. This lack of education clearly had long term consequences, leaving them 'less likely to become employed, and are more likely to remain poor' (Shakespeare, 2012: 276). Others, such as Cuifen, were able to continue schooling but had to compromise to do so. For example she had to overcome her embarrassment at being forced to use a male toilet just because she used a wheelchair at school:

> I felt really upset that I could become like this *lah* [...] The female toilet was located on the upper floor and the male toilet on the ground floor. So I had to go to the male toilet *lor*. I felt really embarrassed using the male toilet because there were male students going there. I was so ashamed but I didn't have a choice. I had to bear with it for the two years I studied there.

The failure of the school authority to provide an accessible female toilet for Cuifen significantly impacted on her psycho-emotional wellbeing as a woman despite her physical needs being met.

4.4.2 Attitudinal barriers in education

As well as structural barriers, many of the women had encountered disabling attitudes from their own family, school authorities and friends in realising their right for education. Yana for example, who came from a rural area, never had the chance to go to school because her parents never wanted to expose her to the public:

> **Yana:** I didn't go to school. I never attended school and only got home tuition [her parents taught her at home]. My family didn't send me to school.
>
> **Me:** What made your family not send you to school?
>
> **Yana:** How I want to say, they didn't have a car at that time. And then, they didn't really bother about it. They thought it would be difficult for me to go to the toilet at school. My family was having some problems. I have some family problems.
>
> **Me:** Family problems? If you don't mind, could you tell me a little bit about it?
>
> **Yana:** I don't know, my family used to be like that. Like for example, when I went out with them to go to the supermarket, they seemed ashamed of me. Yes, they take me out but I can feel that they don't really feel happy. They seemed to avoid pushing my wheelchair.
>
> **Me:** Ehem...They? Who are they?

Yana: My mum and dad.

Yana felt that her parents did not send her to school because they were ashamed of her impairments and this made her feel they did not accept her. As a result of this abandonment she developed low self-esteem which was amplified by the fact that she was not included in the education and in other normal family activities. The consequence of such interactions: social encounters with significant others and the impact they have on an individual's wellbeing are a recurrent theme in this thesis and will be explored in more detail in throughout the data chapters.

For many of the other women the disabling attitudes of their school authorities became a major obstacle to them attaining education. For example Dilah described how her aspiration to excel in education was 'ruined' by her school authorities:

> After I recovered from amputation surgery, I wanted to continue my studies to form four [equal to Year 11 in British secondary education]. So I applied to the local school but they refused my application. They refused because they said that I was so far behind in my studies. Before I fell sick, I had already informed them that I couldn't go to school temporarily. Then, when I wanted to continue my studies after recovery they didn't allow me [...] I felt so frustrated and upset. I'm not praising myself but I had been a good student ever since primary school. I always got good grades in my class. So I thought I could excel in my studies but unfortunately I can't.

Despite the disabling attitudes displayed by parents and school authorities, some of the women also had to deal with the negative attitudes exhibited by their friends at school. Cuifen, who lived in an urban area, described how she was not only discriminated against by her school authority but was also bullied by her school friends:

> During school days, I was always being bullied by my friends until I wanted to quit school [...] Then I informed my mum that I didn't want to go to school. She asked me why I didn't want to go to school. I said *lah* there were students who beat me, they bullied me, and some of them put nails in my wheelchair tyre. So my dad was angry. He went to see the headmaster. Then he went to the Welfare Department and warned the headmaster that he had no right to dismiss me from the school. After the headmaster received the letter only then he allowed me to

> continue my studies. I felt very upset by such incidents as if I was like an unwanted student in the school.

Similarly Nadia, who came from a village, also described the culture of intimidation and bullying that she experienced at school due to her impairment:

> When I was at school, all of my classes were located on ground floors as I could not take stairs with my wheelchair. Some of my classmates were angry at me. They scolded me for going to school as I had caused them to not be able to have a classroom on the upper floors. They felt that I was troublesome and I should just stay at home rather than going to school. They were dissatisfied with me too, as many teachers gave priority to me and they got jealous. I was upset but I couldn't do anything. That's why I had very few friends at school.

This section has shown how the participants from both the urban and rural areas were prevented from getting formal education due to their impairment as a result of negative attitudes displayed by their parents, school authorities, and school friends. They not only experienced structural and attitudinal barriers in realising their right for proper education but also had problems getting adequate training as discussed next.

4.4.3 Limited opportunities for training

More than 50 percent of the women interviewed attended vocational training for disabled people at least once in their lifetime; regardless of their educational background. 12 out of the 17 Malay informants received vocational training from at least one disabled person's institution, three out of the eight Chinese participants also attended a vocational training course at a disabled person's institution, and two out of the eight Indian women did the same. The majority of them came from rural areas and low-income families and as such the vocational training provided by the state and the NGOs became one of the best options that they had.

Although many women underwent vocational training for disabled people, some of them discovered there were narrow prospects for gaining access to their desired training course. The vocational courses in the rehabilitation centre offered by the state (DSW) were very limited and gender-based. For example

Yasmin who acquired her impairment at the age of 16 described how she had limited opportunities to choose a course that she liked:

> I didn't take the SPM. I spent about two years in my room. Then, I heard from a radio station that there was a rehabilitation centre for disabled people in X. I applied and accepted. I was actually intending to take the SPM in the centre but unfortunately they only offered vocational courses like tailoring, repairing radios and TVs. So as a female, I could only choose tailoring to study, which I didn't like. So I didn't actually learn and just stayed there for like a year. Then after a year I came back home.

Yasmin decided to continue her education in the rehabilitation centre for disabled people after she acquired her impairment. In her case, the inaccessibility of the local mainstream school did not allow her to attend. At the same time, like many of the other women interviewed, she felt unable to continue schooling with non-disabled peers because she was afraid that they could not accept her disability. Therefore her academic ambitions and aim of taking the most vital exam (SPM) in Malaysia was not realised - neither in the mainstream school nor in the rehabilitation centre for disabled people. Thus she was denied her right for proper education and training. Similarly Intan was also not given a choice when selecting her vocational course:

> I studied there [a rehabilitation centre for disabled people] in 1985. I learnt tailoring. At that time we had three classes for tailoring and all of them were full. The majority were female students. I was not really interested in tailoring actually. That was the only available course for girls. All girls went for the tailoring course and boys went for the one repairing radios, TVs and cars. So, I just learnt it as it was the only option I had.

Whereas Nadia had to quit her vocational training programme because she was not fully allowed to study her desired course: instead she was assigned to tailoring:

> I studied full time tailoring and part-time computing [IT course] there. It was a two year programme but I quit after 1 year and five months. I told the deputy director [of the vocational centre] that I wanted to study computing full time because I didn't like tailoring. However he didn't allow me to change my course and therefore I quit.

The vocational courses offered by the state were often based on traditional gender roles, and women were assigned to crafts, or feminine courses like tailoring; while men were enrolled on mechanical courses, such as repairing cars, televisions, and radios. Such gender bias in vocational training for disabled women may have impeded their full potential for employment or career development as discussed earlier. This suggests 'multiple discrimination' was practised against these women, making them feel at a greater disadvantage because not only were they trained for work which would result in low paid positions, but they were also restricted to only 'feminine work'.

However despite these inadequacies, some women really benefited from the vocational training provided in the rehabilitation centre for disabled people. Eryna, who acquired her impairment at the age of 16, described how she overcame her fear and embarrassment over studying a course designed for males to improve her employment prospects:

> I took two courses in the centre; tailoring and also repairing radios and TVs. At that time, I was the only girl studying the course because normally only boys do the radio and TV course. Sometimes, I was not comfortable having attention in the class because they were all men. They used to stared at me and tease me. But, I just ignored them because I really wanted to study hard

From the above examples it can be seen that although the DSW provided vocational training for disabled people it was limited and discriminatory; especially for disabled women. Not only did such restrictions prevent these women from having equal access to education and training but they also brought long-term negative outcomes; as articulated by Farah:

> That's why I said, it is very hard for disabled people to find a job. The environment is not disability-friendly and that's why it is difficult. Also, to find a better job is impossible because I don't have a high education level. That's why I have only one option – working in this workshop.

This case was a good example of the dynamic interaction between poverty, poor health services, geography and disablement. Farah, as discussed earlier (see 4.2.1), had limited access to healthcare because she lived in a very remote area where healthcare services were unavailable and she was born to a poor family that prevented her from having access to transportation. The limited access to healthcare contributed to the onset of a permanent impairment which, in turn, meant that she encountered barriers when she went to school and subsequently had to quit because the school was not accessible for her. Therefore, with low academic qualifications, she had limited opportunities for employment except to secure a job at a workshop for disabled people with a low income, and this made little positive impact on the poverty she experienced at the time.

4.5 Employment

The women interviewed had a range of employment experience. The majority of them (25) were currently working at various levels, while seven of them were not working and one was still studying. Of the 25 working women, seven were working in a residential workshop for disabled people, seven were working with NGOs, three were working from home, three were working at a professional level, and five were working at a non-professional level.

The majority (24) of them received a Disabled Employee Allowance (EPC, see Chapter 1, 1.3.2). Those who received the EPC had on average RM50 (£9.16) to RM1200 (£219.78) income per month. This can be regarded as very low considering that the mean household income for Malaysian in 2009 was RM4,025 (£737.18) per month (Department of Statistics Malaysia, 2012). Thus, it can be argued that the majority of participants had a very low income, even when they managed to secure employment.

4.5.1 Structural barriers to employment

As observed in the previous sections on healthcare, transportation, and education and training structural barriers in the workplace also became the main issue for many of the women interviewed. Many participants were unable to take up their desired job because the workplace was not accessible for them.

Yana for example, expressed her disappointment at how environmental barriers had denied her the opportunity for employment:

> After I finished my tailoring training at the rehabilitation centre, I went home. Then I got a few job offers. But I couldn’t take them

> because all the shops were located on upper floors. One of them was offered by a disabled employer [crutches user]. But her shop was also located on level 1. So, I had to let it go as I couldn't take steps with my wheelchair.

In Malaysia, tailoring is a low paid job and most of the tailoring is done in inaccessible workshops on the first floor above a shop because the rent is cheaper compared to offices on the ground floor. It suggests that the physical environment for tailoring jobs in Malaysia is not designed to include people with mobility impairment, especially wheelchair users. Nevertheless, most of vocational centres for disabled people run by the DSW and the NGOs are offering a tailoring course as one of their main training courses for people with physical impairment; especially for women. Consequently, despite having tailoring skills, many of the women had found that they were unable to secure employment because of this structural barrier.

Likewise, Imah described:

> My third job was with a tele-marketing company. I did not work for long - it was only six months. I had to quit because the company asked me to go outside to find the clients. It was a credit card company. Before this – when I started the work, I was never asked to work outside the office, because it was hard for me since I use a wheelchair, so I decided to resign. It was a hard decision for me because I had difficulty finding a job after that. I was unemployed for almost a year after I quit from the company. At that time I felt so helpless because I had some bills to pay and my family started to ask me when I would get a job. It was really tough for me at that time.

As wheelchair users these women had limited access to the workplace building and outdoor working environment because many public places were not accessible to them. It was not only the physical environment that prevented them from taking the employment but the nature of their impairment itself limited their ability to work in certain types of work such as those located in an outdoor working environment. This thus suggests that both the structural barriers, and nature of impairment, acted as barriers to undertaking employment. Therefore limited employment opportunities and abilities for women with mobility impairment, especially regarding for those in wheelchairs, prevented them from having secure financial prospects and as such it led to poverty.

4.5.2 Attitudinal barriers and discrimination in employment

Many of the women interviewed not only encountered structural barriers in the workplace but also met with negative attitudes from both employers and prospective employers. Zahra told how constant rejection from potential employers just because she used a wheelchair made her feel worthless:

> Companies out there don't want to take on disabled people who use a wheelchair, like me. I felt so upset and wanted to cry at that time when they looked down on me. Why? Do those of us in a wheelchair not deserve to work? One of the employers said to me 'miss, there is no need for you to bring your certificates while you are still in a wheelchair'. I was so upset. I went for job interviews so many times until I became frustrated and went back to my hometown.

Despite having vocational training in computing from the DSW, it did not exempt her from such discrimination in employment. As a result, she ended up in a sheltered employment for disabled people for 10 years.

Many of the women were not only discriminated against when seeking employment; even when they had secured employment they were still oppressed by their employer as described by Wei Yin:

> My first job was so terrible. I was 'kicked off' [dismissed] by my boss on the first day. He said that the work was not suitable for me. He was afraid that I might fall down at the workplace. Maybe he thought I was not capable as he looked at the way I walked [she had polio and used callipers].

Similarly, Pushpa also faced discrimination from her employer - just because she requested an accessible toilet at her workplace:

> After six months working, I approached my boss. I told my boss, 'boss, if you don't mind I want to make a proposal for a disabled toilet *lah*'. He said to me, '*aiya,* you're the only disabled one working here, why should I spend so much money on a toilet for you?' […] Then the manager told me he could not give me a toilet […] What he did was, he said, 'if you're happy with the job, you stay, if you're not happy, you can leave'. He said it like that but I still didn't want to leave my job. After six months, he dismissed me with one week's notice. Then I filed a report to MTUC [Malaysian Trade Union Congress].

Pushpa’s refusal to accept such discrimination resulted in a successful compensation of three months payment through a mediation initiated by the MTUC between her and her former employer. Whilst she was able to exercise her agency, the structural and attitudinal barriers that she experienced in employment resulted in significant psycho-emotional impact on her wellbeing.

4.5.3 Sheltered (secluded) employment

As mentioned above, seven women were working in a sheltered or secured employment for disabled people in a rural area run by an NGO. Most of them decided to take this employment because they were unable to find a suitable job with accessible transport and accommodation. Therefore they took the employment and lived in a hostel provided in the workshop.

Their main job in the workshop was folding envelopes for governmental agencies from 8am to 5pm, five days per week. Although they were provided with free accommodation, the income they received was very low when compared to the mean household income for Malaysians (Department of Statistics Malaysia, 2012). All except one of them lived in the institution and far from their family. Two of them had lived there for more than 10 years and they never had opportunity to find a job or live outside the workshop.

Besides having low incomes, these women were also marginalised and excluded from society at large. The workshop was located in a remote area, far from the city and as such restricted their opportunities for wider economic and social activities. Most of their time was spent in the workshop with their disabled friends. They were also constrained by the rules in the workshop that restricted them from pursuing leisure activities. The majority of women described how they had mundane routines in the workshop that made them feel bored and lonely as they lived far from families, friends, and the city.

Shanti spent 12 years in the workshop and described the social restrictions in place:

> They did not allow me to go out. They said that the police would catch me because I wanted to go out with my best friend there who was learning disabled. We didn’t want to do bad things we just wanted to

> go shopping. I also wanted to have leisure activities like other people out there.

Although the institution permitted its residents to go out during weekends, Shanti was an exception to this rule. The workshop management staff did not allow her to go out during the weekends because she wanted to bring along her best friend who had a learning disability. As she was physically impaired she needed help from her best friend to push her wheelchair. She felt discriminated against by her organisation as her autonomy and right for leisure activities were compromised. This significantly impacted on her psycho-emotional wellbeing.

Despite some rules in the workshop, some of the women felt socially isolated due to their low income. For example Zahra, who had lived for 10 years in the institution, told how she spent most of her time in the workshop because she could not afford to have leisure activities outside it:

> At the weekends, most of the time I prefer to stay in the hostel doing my work like cleaning my room, watching TV or reading books. I know that it’s boring but I have no choice. I will only go out if I have extra money. You know that I only receive RM100 for my salary and RM300 for the EPC. So, I can’t afford going out for shopping. I rarely going out, sometimes I just ask my friend to help me buy things when they go out. If I go out I need to pay the taxi, food and many other things

Therefore Zahra’s poverty intersected with disablism and consequently it undermined her wellbeing. The examples given by the women of their experiences in the sheltered employment scheme clearly showed how they were systematically excluded from wider social activities and lived in an isolated environment, although they had a (low paid) job. It thus suggests that they were ‘trapped’ in a perpetual cycle of poverty, being excluded from developmental opportunities, and subjected to social isolation.

4.6 Housing

In the previous sections it was observed that many women were excluded from wider social activities due to the failure of the built environment to accommodate their impairment needs. This was also found to be very significant in the home settings, especially for those who lived in poverty and in rural areas. Many rural houses, especially in villages and estates, were built with steps. Similarly many houses in urban areas were also inaccessible as they were built a long time ago, before any awareness of the need for accessible housing existed, and well before any state intervention. Therefore many participants described accessibility issues and disabling attitudes in their home environment. This section will explore how structural and attitudinal barriers in a home setting significantly impacted upon these women.

4.6.1 Access to housing

Two of the women related how they had to spend most of their childhood and teenage years living in institutions for disabled people because their home was completely inaccessible. Huifang described:

> You know, we lived in an estate house. [There were] no facilities at all for me. [...] So I had to live in a children's home [run by the DSW] near to my hometown from an early age.

Likewise Rupa explained how poverty significantly impacted upon her life. She lost her father before she was born and that made her mother's life difficult as the family had no stable income. With little income her mother could only afford to rent a small room in an estate which was inaccessible to Rupa. She described the impact of this and the impossible choice it left her mother:

> I lived in the residential institution because of an incident […] One day my mum left me in a local shop because she was unable to carry me to her workplace [as a home helper doing laundry, cooking and cleaning]. After a few hours, I was crying because she did not return. Then the shopkeeper reported it to the police and I was brought by them all over the estate to find my mother but we couldn't find her. Then, they brought me to the Welfare Department and they put me in a residential institution. After a week my mother came to look after me after finding out that I was in the institution. Since my mother was so poor and she only rented a small room which was not accessible to me, she asked me to live there while she came and visited me every two weeks.

Meanwhile Ainul had difficulty in accessing her parents' house in the city after she became disabled in a road accident. Due to a spinal cord injury, she became paralysed and had to use a wheelchair:

> My parents' house is on the upper floor. A few doors downstairs were rented to some tenants. The house is very high, like a traditional Malay house in the villages […]. We have to take a number of steps before entering our house. So, whenever I want to go in and out from the house, I need at least two people to carry me and my wheelchair […] It was so difficult for me to go to a medical check-up and physiotherapy. After a few months, my father provided hand rails at home for me to do exercises and after that I no longer went to physiotherapy sessions.

Clearly these types of problems in the home setting frustrated the participants' opportunity to live with their family and get access to healthcare services. As well as the effects of poverty and inaccessible housing, many of the women also encountered the disabling attitudes of local authorities and their neighbours in getting access to their home.

4.6.2 Disabling attitudes in housing

Accessibility issues in the home not only occurred in rural areas but also in urban locations. This was primarily due to the fact that many buildings were old. Only in recent years have the government emphasised the need to provide an accessible built environment for disabled people, especially after the implementation of the PWDA 2008 (Persons with Disabilities Act 2008, 2008). Nevertheless the focus for discussion in this section is the attitudes of local authorities and other residents towards the physical needs of the women interviewed.

For example Rupa's housing problems, experienced earlier in life (see 4.6.1), remained a recurrent problem. After finishing her studies and working with a governmental agency, she applied to live in accommodation provided for civil servants. She managed to secure an old flat on the ground floor with a few steps at the entrance level and requested that the local authorities provide a ramp for her to allow easy access to the building. However, she found their attitude disappointing and withdrew her application:

> My current flat doesn't really have facilities for me. It is an old building and there is no parking for the disabled. It has no ramp too. So I asked them if they could provide a ramp to grant me access into the building [because she was a wheelchair user]. Instead of using a wheelchair, I needed to use crutches to take a few steps at the entrance level. However, they said that if they provide a ramp, then

> other residents would bring their motorcycles and bicycles into the building. So they were not really happy to do that. But they asked me to write a letter to them to apply for the ramp. Until now I still have not written the letter because I don't feel good bringing troubles to other people.

4.7 Family separation

In this chapter it has been discussed how many of the participants had encountered structural and attitudinal barriers in accessing healthcare, transportation, education and training, employment, and housing. This was primarily contributed to by the factors of geography, finance, and impairment experienced by the majority of women. In relation to that many of the women, some with their families, migrated to urban areas or cities for the purposes of education or training and employment. This section will examine how rurality, poverty, and disablement contributed to family separation.

Many women had to live away from their family: because their home was inaccessible, they could not find accessible work or training in their home community, or because they had to move for reasons of health and social care. In addition the families of some women also had to be split up to cater for the needs of their disabled daughters.

For instance Lijuan migrated to the city so that she could attend vocational training for disabled people. Her subsequent job and marriage led her to settle there. In the early stages of this move her mother had had to leave the family in order to physically support Lijuan and her disabled brother throughout their studies in the absence of support from the welfare state:

> I went to study at the institute for disabled people in 2000. My younger brother who has the same physical condition as me also came to the institute to study. My mother had to look after both of us and left my father and family back home. Every day she had to push our wheelchairs to attend classes, take bath, and everything else. She used to be with us 24 hours to cater our daily needs in the institution.

It was apparent that this situation led to the physical and emotional separation of the family - between her mother and her father and her siblings. This was predominantly caused by a lack of support from the welfare state - the unavailability of accessible training for disabled people in rural areas and inaccessible schooling prior to this (see 4.4.1). As is apparent from Lijuan's family story, they had to sacrifice their family life in order to support her needs in the city. Therefore rurality, poverty, impairment, structural barriers, and lack of support from the welfare state not only affected the disabled women directly, but also their impacted upon their families' wellbeing. This issue thus sets the agenda for the analysis in the following chapter on family.

4.8 Conclusion

This chapter shows how rurality, poverty and impairment have a direct causal relationship in shaping the lives of Malaysian disabled women. By analysing their experiences of disablement, the data has shown that economics and geography played a central role in how disability was experienced in many aspects of their lives – healthcare, transportation, education and training, employment, housing, and family life. For a developing country like Malaysia it was important to observe how a lack of accessibility both in rural and urban areas, and poverty, had significantly impacted disabled women's wellbeing in terms of their physical and psycho-emotional needs. At the same time, lack of support from the welfare state and societal disabling attitudes towards these women also played important roles in excluding them from wider social and economic activities. Nevertheless this was not a simple issue for these women. It can be observed that there was a complex intersection between geography, finance, impairment, societal norms, structural and attitudinal barriers and also gender in shaping disablement in the women's lives.

In expressing their healthcare experiences the women observed that rurality and poverty increased the risks of acquiring impairment because modern medical healthcare was inaccessible to many of them. Lack of healthcare services in rural areas often made them dependent on the traditional treatments offered by local shaman or religious persons. This encouraged a strong cultural belief in the effectiveness of traditional remedies rather than modern medical treatments. Due to a strong dependence on traditional remedies some women were exposed to financial and sexual exploitation by the traditional healers. However these incidents were never revealed to the authorities as the perpetrator was usually known to the family of these women. Likewise unethical practices also occurred in modern medical healthcare as some of the women described how they were subjected to sexual abuse and mistreatment by their physicians. Such unethical practices prevented some of the women from continuing their medical treatment, leaving them permanently disabled.

Not only did they face various issues in healthcare, many of the women also encountered significant barriers in accessing public transport. Many of those interviewed told of how public buses and trains were not accessible to them; especially those in wheelchairs. As such many of them had to spend extra money to hire taxis. Nevertheless they were even more frustrated with the attitudes of many taxi drivers who often refused to take them in wheelchairs. This caused psycho-emotional distress to many women as they felt humiliated and discriminated against because of their impairment. This was also closely linked to their low economic status that made them unable to have their own transportation despite the poor public transport system in Malaysia. Thus many women were denied their rights and the opportunity to become involved in wider social and economic activities.

Geography and finance again also affected the educational and training experiences of many of the women interviewed. In many cases women missed out on school because their school was inaccessible to them. These types of structural barriers experienced at school also led to attitudinal barriers displayed by school authorities and their friends. Both a disabling environment and attitudes within educational settings hindered the opportunity for equal education for many women causing them to have a poor education that affected their career choice. Likewise many of the women had limited opportunities, not only in formal education, but also in vocational training provided by the state and the NGOs. It was observed that the courses offered were very limited, gendered-based and discriminatory. Therefore it barred many women from having wider prospects in employment and restricted their full potential as active agents in society.

The structural and attitudinal barriers were not only experienced in educational settings but also in employment settings. Many of those interviewed were prevented from taking up their desired employment because of inaccessible built environments. Many were also prohibited from securing mainstream employment because prospective employers often had negative attitudes towards their ability to work; again especially true for those in wheelchairs. Also some of them were restricted to certain types of job due to their impairment. Consequently many of them took up sheltered employment for disabled people that marginalised them from the larger society. They were not only secluded from wider social activities but they also had very low incomes that increased the danger of poverty. Therefore structural and attitudinal barriers that hindered equal opportunity for transportation and education systematically prevented their prospects for employment, leading them to poverty.

Many women not only faced constant struggles in getting access to healthcare, transport, education or training and employment; they were also disadvantaged in their home settings. Some of them, especially those who lived in poverty and rural areas, had been prevented from living with their family at home as it was inaccessible to them. Also negative attitudes displayed by local authorities and other residents denied equal access for housing to those in wheelchairs. Once again, this significantly affected the physical and psycho-emotional wellbeing of these women.

As discussed throughout this chapter, poverty and rurality had dramatically impacted upon disabled women's lives in many aspects related to poor accessibility and societal disabling attitudes towards them. Consequently many women and their families had to move from rural areas to urban areas to have better access to healthcare, transport, education and training and employment. In some cases the family had to be separated where one of the parents had to leave the family back home in order to support their disabled daughters in the city. It was found that disability and rurality could split up the family, significantly affecting not only the disabled women themselves but also their family as a whole. This issue will become a central focus of discussion in the next chapter on family.

Most of disablement experiences discussed in this chapter led to these women to experience what Thomas (2007) termed as 'psycho-emotional disablism'. This further explained by Reeve (2008; 2012) as 'direct psycho-emotional disablism' (disabling attitudes) and 'indirect psycho-emotional disablism' (structural barriers) that damaged one's self-worth. The extended version of 'psycho-emotional disablism' (direct and indirect) proposed by Reeve was difficult to apply in the analysis. It was hard to distinguish which psycho-emotional impact was inflicted by the attitudinal barriers and which by the structural barriers as they worked together simultaneously and sometimes the distinction between the two was blurred. Whilst the concept of 'psycho-emotional disablism' is very useful in explaining the research findings, it does not include the role of impairment, poverty, geography, gender and culture within the disability experiences. This chapter has showed how the structural barriers, attitudinal barriers, impairment, poverty, rurality, gender issues and cultural norms significantly impacted on the lives of the majority of participants undermining their physical, psychological and emotional wellbeing in both the short and long term. Rather than using a simplistic explanation of psycho-emotional disablism proposed by Thomas and Reeve, I would rather use a complex analysis of psycho-emotional disablism in analysing the participants' disablement experiences.

Hence this chapter presents strong proof of the complex disablement and 'psycho-emotional disablism' that these women suffered, excluding them from wider social participation and economic activities. This complex interplay of disablement experiences, including the role of structural and attitudinal barriers, impairment, poverty, rurality, gender, and cultural norms, significantly influenced their familial interactions. It is their family relationships that we will examine next.

Chapter 5: Family

5.1 Introduction

The previous chapter uncovered how the majority of women interviewed were marginalised from wider social participation and economic activities as a result of the complex interactions between rurality, poverty, impairment, gender, structural and attitudinal barriers. The disablement experiences not only affected these women but also their family[13] as many of them had to support their disabled family members. Many of the women also had to leave their family and hometown in order to obtain accessible training and education, and employment and housing; and thus it led to physical and psychological isolation. This chapter will set out the role played by the family and how it impacted on the women's lives and how the disability experiences, including this combined with other factors, in particular the inadequacy of the welfare state to influence their physical and psycho-emotional wellbeing, as well as familial relationships.

Malaysia is a collective society that places emphasis on unity and a sense of belonging to family and still 'preserves many traditional values while adopting an increasingly international outlook' (Kennedy, 2002: 15). Chapter 1 discussed how family plays a crucial role in the lives of the majority of Malaysians, especially women. The data gathered in the research continued to support this observation of familial roles and family remained a central focus of the participants' lives. It was observed that the majority of participants were supported by their family and thus had a pivotal role for them. This reinforced a strong notion of traditional care being widely practised in Malaysian society based on mutual understanding and interdependent relationships within family. Therefore this chapter will explore the dynamic relationships of such caring roles and experiences within the framework of a feminist ethic of care.

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[13] Family in this chapter refers to parents, siblings and grandparents of the research participants. It does not include their husband or their husband's family, or their children or grandchildren for the married women. This will be explored in the next chapter on love, marriage and motherhood.

Tronto (1993) suggests that the feminist ethic of care is based on relationships and responsibilities. The ethic of care develops from concrete circumstances and depends on activity. From the caring activities and responsibilities the concept of interdependency and mutual need emerge (Fraser, 1989; Watson et al., 2004; Hughes et al., 2005). Kittay (1999) argues that in meeting the need of care we cannot exclude the reality of dependency within such caring relationships as,

> Once we stop ignoring dependency, then we are obligated to think of how dependency needs are met in a manner that is equitable to all (Kittay, 1999: 90).

Over our lifespan we are all interdependent upon each other as we will both require and give care at various points. Such interdependence of caring taxonomy involves both an emotional relationship and an element of physical care (Watson et al., 2004) as 'care as a practice invokes different experiences, different meanings, different contexts and multiple relations of power' (Williams, 2001: 468). Hence 'caring expresses ethically significant ways in which we matter to each other' (Bowden, 1997: 1). Therefore this chapter will explore how the women interviewed experienced care within (or outside) their familial environment and how the different disability experiences, gender, location, economic, cultural and familial relationships influenced their lives.

5.2 Family care

The majority of participants described their family as central to their lives and it was seen by many as their primary source of care and support. However for many women this created a double bind. Whilst on the one hand they would normally look to their family for care and support the inadequacy of the welfare state in terms of support for accessible housing, education and training, and employment in their hometown forced them to live away from their family. This led them to experience both physical and psychological isolation from their family members. Nonetheless the psychological isolation could also occur within a familial environment as this section will show. In addition family conflicts existed as a result of the effects of impairment, sibling rivalry and emotional isolation within the family. This section therefore will explore how the varying levels of familial support the women received (or not) impacted upon their psycho-emotional wellbeing and how this affected their lives.

5.2.1 The primary care

The majority of the participants' experience showed that the traditional care within family was still dominant in Malaysian society. Lynch et al.(2009) defined this type of care relation as 'primary care', one that has an intimate attachment and is characterised by an interdependent relationship. This affective system of care within a family is concerned with providing and sustaining the familial relationships with love, care, and solidarity.

For example Deepa described how her family was so central in her life, especially after she acquired her impairment:

> I mean for me my family is first. Family definitely first. So I mean I'm glad I come from a big family. 11 of us, one passed away [...]. They have been very supportive ever since I became disabled. Although both our mum and dad had passed away, we are all still very close. They're coming tomorrow [...]

Deepa became paralysed in a road accident during her second year at university. When she returned to campus after recovered from her injuries, her eldest sister had to come and support her on campus for day-to-day activities because there was no care support provided by the welfare state. For many of the women interviewed the principal care within their family was predominantly provided by their parents. This type of care relation is referred to as 'love labour'; symbolising the parent-child relationship (Lynch et al., 2009). The 'love labouring' in primary care relation involves 'the world of primary, intimate relations where there is strong attachment, interdependence, depth of engagement and intensity; the prototypical relationship in this circle is that between parents and children' (Lynch, 2007: 555). As Nisa expressed:

> My parents always supported me especially my mother. Although my father passed away, he was the one who sacrificed a lot to see me recover from my illness [...]. Now after my father had gone, my mother and sisters are the most important people in my life.

For many of the women, the love, care and support exhibited by their parents was believed to be due to their impairment as Jiaying said:

> I think my parents gave extra love to me, more than my brothers and sisters. They paid extra attention to me because I have an impairment […] I miss my father since he passed away […] At this moment, my mother, my sisters, my brothers, all my relatives are important to me.

Therefore the impairment reinforced a strong interdependent relationship between these women and their parents, as well as other family members, because they were regarded as needing most support in the family. It was also observed that the majority of the women, regardless of ethnicity, had strong support from, and a good relationship with, their family. For most of them family was regarded as the most pivotal aspect of their life because the primary care was provided mainly by their own family members rather than the welfare state or others. However not all of the women had the opportunity to be cared for within a familial environment because of poverty and structural barriers. This is examined in the next section.

5.2.2 Isolation

The majority of the women come from low-income families and lived in poverty and rurality. Consequently some of the women had to grow up in a residential institution for disabled people from a very young age because their family could not afford to support them and their family's housing was inaccessible to them (see 4.6.1). Not only did this cause these women to experience physical separation but it also resulted in psychological isolation from their family as this section will show.

Rupa (see 4.6.1), who spent most of her childhood and young adulthood in a residential institution run by the state, had never lived at home and consequently had never spent significant periods of time with her mother; an arrangement that she appeared to be content with. However such physical separation from her mother had a psychological impact their relationship:

> My mum came every two weeks to visit me in the 'charity home' until I finished my secondary [high] school. I rarely went back home because it was difficult for me. She rented a room in my hometown. That room was very difficult for me. Every time when Deepavali [a Hindu festival] came, the institution's workers asked me to go home to celebrate with my mum but I felt worried. I was worried because I had to go home.

> There were no facilities for me, it was difficult. But I had to go back as well because it was a holiday, right? My mum wanted to bring me home. She said it was Deepavali and she wanted to celebrate it with me. Although it was really difficult, I had to go home with her.

Her impairment, her mother's poverty, and inaccessible housing, created psychological distance between Rupa and her mother, something that could have been avoided. If she had received adequate support from the state in terms of financial benefits and accessible housing, Rupa and her mother could have lived together and would have had the opportunity to develop a more intimate parent-child relationship within a familial environment.

The experience of living in a residential institution during childhood not only affected the parent-child relationship but also the relationship with other family members. Such familial separation could be damaging not only to the psychological wellbeing of a disabled child but also to the unity of a family. For instance Huifang (see 4.6.1) described how she was unhappy to return home after finishing her term at a charity institution:

> At the beginning [after she returned home from a disabled institution] I felt happy to live with my sisters and my parents. But then, gradually I felt lonely and isolated from my sisters. It was because they had lots of friends and they always went out for gatherings and birthday parties. They went shopping here and there, but I couldn't do that. It was difficult for me to go out because we had no vehicle. I also couldn't take the bus because it was not accessible for 'handicapped persons'. So I just stayed at home. I was really upset and I felt very isolated. At the time I thought 'why did I become 'handicapped'?

Her impairment and inaccessibility issues at home had made her felt isolated from her siblings; something that she did not experience at the residential institution. Due to many years of living away from her family, she had difficulty adjusting to her familial environment. It made her feel that she did not belong to her family and thus it created anger within her. She became hot-tempered and constantly expressed resentment towards her sisters; an action that further inflamed the atmosphere between her and her sisters. She required extra attention from her mother, which again harmed her relationship with her siblings, and consequently led to feeling unhappy at home. After living at home for a few months, she asked her family to send her to a vocational institution for disabled people. She used studying at the institution as an excuse just to live away from her family's home as she revealed:

> I want to run away from that place [her family home] actually that's why I told them that I want to learn tailoring in the centre […]

This challenged the social norms of Malaysian people that place emphasis on the unity within, and a sense of belonging to, the family. Huifang's disability therefore prevented her from becoming a full member of her family.

Not only did the women have to be separated from their family during childhood but also many of them revealed that they had to leave their family at later age to obtain accessible training and employment. As discussed in Chapter 4 (see 4.7), some families had to be divided to provide support for their disabled daughters in the city. The impact of such physical and emotional separation from family was even greater for women with impairment themselves as they felt that they failed to fulfil their obligation as a daughter to their parents; as Shanti described:

> I came to this workshop [a sheltered employment for disabled people] 10 years ago […]. Before that, I lived with my parents. I loved them so much. As the youngest child, I looked after my parents at home. After the accident [that made her acquired her impairment], they [her parents] always helped me push my wheelchair and helped me to go to the toilet. When they fell sick, I gave them medicine and looked after them. They loved me so much (cracking voice).

Shanti had to leave her elderly parents to secure employment in a sheltered workshop for disabled people because she could not get any employment in her hometown. After she became disabled she had to quit her job and no other local employer was willing or able to grant her employment because of her mobility impairment. The resulting separation from her parents had a long term negative effect on her psychological wellbeing which was intensified when she could not pay her last respect to her parents' bodies when they died because her family members concealed what had happened:

> […] my father suddenly passed away a year ago [when she was living in the institution]. A few months later, my mother passed away (crying)

> […] No one informed me when my mother passed away. I was so upset and devastated (crying).

For the majority of Malaysians, family plays a central role; especially the parental relationship. For Shanti her inability to 'serve' her parents before they died, and her 'failure' to visit their mortal remains, made her feel regret and guilt; psychological burdens she felt she would carry for the rest of her life. Therefore not only did her disability restrict her ability to work and participate in society but it also the attitude of her family denied her the opportunity to look after her parents, as well as to be cared for by them and to carry out the normal duties she associated with being a daughter.

5.2.3 Family conflict

The previous sections discussed how culturally in Malaysia the family is expected to provide primary care for the majority of women and how poverty, inaccessible housing, training and employment, as well as discrimination against women in employment, had driven the women from their family. Such consequences were linked to the fact that these women had an impairment that influenced how they received support within or outside their familial environment. This section will explore how care and support given to women with impairment in their family could create conflicts and tension amongst family members.

As observed in 5.2.1, many women perceived that they were given considerable support from their parents and other family members because they had an impairment. The 'extra attention' that the women received as disabled children often created internal conflict within their families. Wei Yin gave a clear example of how extra attention given to her by her father made her become the centre of the family, creating resentment and conflict between herself and her other family members, including her own mother:

> When I was small, I always blamed my parents for having Polio. I thought it was their fault. So at home I was like a king! I have a very strong character. If I don't like something I will just throw it out. No matter whether it was rubbish, glass or even a knife I would just throw it. So, every time I threw something, my mum would beat me with a cane. Later at night, my father pampered me and bought a lot of food

> to comfort me. When I had an argument with my mum, my father always supported me. He scolded my mum because he said I was disabled and my mind was not stable like others. So I always took advantage of it. My brothers and sisters would not dare to speak to me. I was the one who could talk to them. If I had any argument with my siblings and mum, I would tell my father. He would scold them back and it was always their fault. So, my mum and siblings didn't really like me because my father always pampered me at home. Up until now, if I wanted something, I would get it no matter what. I would always get what I want.

Likewise Imah also had conflict with her brothers and sisters as her late father paid extra attention to her in the family. It caused them to dislike her and to verbally abuse her:

> In my life my late father was the one who always supported me. He never said no to what I wanted to do in my life. He was the best teacher for me. He never looked down on my disability. He always believed I could be like other people. He believed in me [...] When my father passed away, I had no one to lean on. My brothers and sisters never tried to understand me. They always challenged me to prove to them that I could be independent without depending on them. Some of them said 'we want to see how long you can survive without our help'. It really hurts to know that your own siblings looked down on you.

As a direct result of this treatment she developed low self-esteem. The extra attention given to disabled children by parents in a family could create internal conflict among family members. It could generate a sense of jealousy among siblings as 'because of the extra attention required by a disabled child, siblings may receive less attention from their parents than they require' (Darling, 1987: 53). They may hold the one who takes all the attention to be their rival and as such lead to sibling rivalry. Therefore despite positive support and care given by parents to disabled child, sometimes it could 'threaten' the dynamic of familial relationships and 'jeopardise' the family's harmony.

5.3 Negotiating self within family

Whilst the majority of women received positive support from their family, some of them, as discussed above, did not. This section will explore how these women negotiated their identity within their family from the varying levels of support they received from them.

5.3.1 Unwanted child?

Some women revealed that their family had a negative attitude towards their impairment; either explicitly or implicitly. Perhaps the most significant experience was described by Dilah. She was diagnosed with bone cancer at the age of 14 and two years later one of her legs had to be amputated. This created tension over her relationship with her father and her grandmother because they could not accept her losing her leg and being disabled:

> When the doctors said that they want to amputate my leg, my grandmother and my father couldn't accept it [after her parents divorced, she lived with her grandparents]. I was too ill at that time. I always lost consciousness because I was too weak. But my father did not want to be responsible; he refused to follow the doctors' advice to let them amputate my leg. Then after frequently being unconscious, and no longer able to bear the illness, I signed the surgery form myself because my father and my grandmother refused to sign it [she was 14 years old at that time]. I had to do that because the cancer was spreading and I might have lost my life. I still remember that my father said that if I agreed to the amputation of my leg, then I would no longer be his daughter anymore (crying). He couldn't accept it. He said on the day of the amputation surgery, 'if she amputates her leg then who wants to take her can do that because I can't accept her' […] They [her father and grandmother] thought that I might become a burden to them that's why they did not want to be responsible.

It is difficult to imagine how a young girl at the age of 14 years old dealt with such a 'traumatic' experience. She not only had to deal with the fact that she would lose her leg but at the same time she would have to lose her family too as a result. This left her feeling upset, and made her feel like an 'unwanted child' because of her impairment. Fortunately her mother was willing to accept her after the amputation surgery and looked after her at the hospital and took her home:

> I lived with my grandmother after my parents divorced when I was still in the primary school. But then when I lost my leg, my mum looked after me and took me home. You know that people say a mother will never abandon her children; she will always look after them. It was difficult at that time because my family couldn't accept me except my mum. Even though she hadn't looked after me since I was small, but after the amputation surgery she was the one who cared for me and brought me home. At that time she was living with my step-siblings [her mother's children from her second marriage].

Nevertheless the psychological abandonment of a disabled child was not only seen through the explicit rejection by the family members but it also occurred implicitly within a familial environment. For example Yana expressed her disappointment over her parents' attitude towards her as she felt that they could not accept her impairment. She was born with an impairment and was raised by her parents in the family home. She was treated differently by her parents in comparison to her brothers and sisters, although she was the eldest child. Yana explained how she had been shunned by them in the presence of other people:

> I still remember ever since I was small, my parents always asked me to go to my room whenever people came to our house. Maybe they felt ashamed of people knowing that I was their daughter [...]. They never took me to go to our family's wedding ceremonies [...] I never met any neighbours; I did not know anyone in our neighbourhood [...] When I go shopping with my parents, they seem unhappy. Yes, they take me out but I can see from their faces that they are not really happy.

Although they did not explicitly 'reject' her, she could feel that she was not a full member of the family and felt herself as an 'unwanted child'. It seems that her parents tried to 'hide' her from the public and this created 'distance' within the space that they lived together. It suggests that both the explicit and implicit 'rejection' from family members, especially the parents, brought negative outcomes for these women undermining their self-worth within the family.

5.3.2 A burden to family?

Despite being accepted by her mother, Dilah (as discussed in 5.3.1) experienced strong 'rejection' by other family members, particularly her step siblings. This made her believe that she was really a burden to the family because she had an impairment:

> After the surgery, my mum took me home with her. However my step-siblings could not accept me at all. Everything was wrong at that time. Sometimes when I cooked, they did not want to eat. My step-brother overturned the plate when I cooked for him. I felt so upset and humiliated. I know that they were afraid that I would become a burden to them. They must thought that I would be dependent on them that's why they treated me badly [...]

However not all women felt that they were a burden to the family because of the negative treatment that they received from their family members; some of them felt 'guilty' and a burden to their family because they were supported so much by them. For example Cuifen expressed her sense of guilt over her parents' loss of their property to pay towards her medical expenses:

> My father sacrificed a lot. He sold his house and his car for me. He sold everything that could give him money to sponsor my surgery […] I felt so guilty that because of me my parents had lost so many things.

The above example shows that the absence of strong support from the welfare state significantly impacted on the wellbeing of the family. Lack of state financial and medical support to fulfil the needs of a disabled child led to financial difficulties within the family and this not only impacted on the physical wellbeing of the child but also on the psycho-emotional development of the child. However such feelings of 'guilt' and being a 'burden' were not only caused by financial loss within the family but also by academic restrictions as related by Alice Chong:

> I feel very sorry for my sister because she had to quit school in order to help me. She was asked by my parents to help me to carry my school's bag and my stuffs at school. So because of me she had to quit school and I can't do anything for her […]

Alice Chong's disability did not only affect her but also her sister from getting equal access to education. Consequently due to her poor educational attainment, her sister had restricted opportunities for employment and remained unmarried into her old age. However this was not only a question regarding the inadequacy of the welfare state but it was also about the state of interdependency within a care relationship. Some feminists argue that independence should be replaced by the concept of interdependence (Hughes et al., 2005: 259) as 'reciprocity is an important factor in social relationships' (Shakespeare, 2006: 146). People receive support and give support in the family and society as part of their productive contribution during their lifespan. So when these women could only receive help but were unable to provide help to their family members, they felt indebted (Shakespeare, 2006): thus it left them with long term psycho-emotional costs.

Likewise for some women their impairment was seen as a liability to their family members and this caused them to believe that they were a burden to their family. As Zahra expressed:

> My parents always asked my brothers and sisters to look after me at this workshop [a sheltered employment for disabled people]. They promised my parents [to look after her] but I don't think they really care about me. I know that they think that I am just a burden to them. Like for example, my eldest sister, she lives closer but she never comes to visit me. My brother then bought a car and promised my mum that he would come and bring me home every week but it never happened […] When my mum called asking if my sister comes to visit me, I just said yes because I didn't want to make her sad. So, I don't rely on my siblings to look after me.

The feeling of becoming a burden to family members could be all-embracing to some women; especially for those who developed their impairment at a later age, as described by Deepa:

> There was a time when I had a small tiff with my sister, you know I felt very depressed and when it came, when we came back to the room there was once I felt oh no that I was being a burden to my sister - that her life was also affected. She had to you know, always be around to look after me, so I was so depressed and I had a syringe, an empty syringe with me you know, which I don't know for what reason I brought back from the hospital as a souvenir and somewhere I read that if you inject air bubbles into your bloodstream, you could die, so I took off this and I wanted, I almost did commit suicide you know […]

Again such disturbing psychological impacts resulted from 'internal conflicts' between the self and the family members showed that these women experienced 'psycho-emotional disablism' (Thomas, 1999; 2007; Reeve, 2008; 2012). However this not only resulted from the negative interactions with family members but it also caused by the consequences of an impairment. Deepa not only had to overcome her fear by adjusting to her paralysis, but she also had to cope with the feeling that she was a burden to her family. At such a critical time in her life this added load deeply affected her wellbeing. Acquiring an impairment at any age is very challenging at an individual level, as Bury (1997), Charmaz (1983), and others have pointed out. If feelings of being a burden and of resentment from other family members are added to the personal feelings of vulnerability and pain that result from such an event; it can only worsen the situation. These feelings were magnified by the fact that, for most of these participants, the family was the only form of support available to them. Without family support many of the women interviewed felt that they would simply not survive and this increased their vulnerability and dependency – making them more concerned of how their family felt about them. They were worried about upsetting their family's feelings raising fears that their family would no longer support them. Thus such disability experiences exposed these women to constant physical and psycho-emotional vulnerability.

5.3.3 Being (in)dependent

The previous sections discussed how different levels of support the women received (or not) in the family influenced their wellbeing and their family. Many of the women described how their family provided extra care, attention and support for them because they had an impairment. However this was, on occasions, not without its costs. Many of those interviewed were over-protected and their parents became overly keen to support them resulting in what Oliver termed 'enforced dependency' (Oliver, 1989: 9). People described how they felt overly-dependent on their family and unable to be independent both financially and emotionally. Without adequate support from the welfare state these women could not live on their own and were thus highly dependent on their family.

In this respect, the nature of care provided by the families in this study could be linked to the relationships and responsibilities set out in the feminist ethic of care (Gilligan, 1983; Tronto, 1993). The families, especially the parents of those interviewed, tried to provide the best support to their disabled daughters. Whilst this type of care was important to the majority of women, it could lead to problems of 'disempowerment' as experienced by Nisa:

> My mum did everything for me. Since I was small my parents always prepared everything for me at home, at school and everywhere. After my father passed away, I only had my mother to rely on. I always took her wherever I went even when I had to go outstation for work […] It was always my mum […] Now I have to be prepared for losing her one day sooner or later. How am I going to survive without her?

Being successful in her career and highly respected at work did not help her to build her self-confidence in managing her personal life. She realised that her family (mother) was perhaps over-protective because of her disability and thus it stunted the development of her self-autonomy. She felt incompetent and unable to stand alone without the presence of her mother. Consequently she felt disempowered, in both her private and public life, and this in turn reinforced her dependency on her mother.

On the other hand, Alice Chong resisted such ‘disempowerment’:

> After the SPM [high school], I was trying to look for a job like my friends [...] I really wanted to work because many of my friends were working during the school holidays. I was so pampered by my mum until I didn’t know how to be independent. Everything was done by my mum until I didn’t know how to buy my own clothes and everything, you know. So when I saw my friends were working I wanted to be independent like them. I managed to get a part time job as an assistant in a tailoring shop because the aunty [owner of the shop] felt pity on me. I was so happy! I got a job already! I went back and told my mum that ‘now I could be independent!’

This replicates some similar feelings expressed by disability activists in the Global North for example Watson et al. (2004) have claimed that ‘notions of care are dis-empowering. The person in receipt of care is often assumed to be passive and dependent’ (Watson et al., 2004: 331). However from the experiences of some of the women, this was not always the case. Alice Chong, for example resisted such ‘reinforced dependency’ and challenged herself to prove that she could be an active and able social agent through her work. Hence her first part time job gave her a sense of self-worth and represented her ability to be independent despite her impairment. It enhanced her self-esteem and proved that she was not always dependent on her mother (family). More importantly, it also made others aware that she was an active and able social agent, reinforcing her potential to act independently in their eyes.

Nevertheless for some women, lack of familial support in terms of their material and emotional needs taught them to be less dependent on family. Instead they turned to the state for support and lived in disabled people’s institution. For example Dilah regained her courage and autonomy to lead an independent life, living with disability far away from her family:

> […] I have been so upset with my family [her father, grandmother and step siblings]. They can't accept me at all. I felt so humiliated as I know that I will only become a burden to them. That's why I decided to leave home [her mother's house] when I was 17 years old. I know that my mum loves me but she had to choose between me and my step brothers and sisters. So it's better for me to leave because I don't want to burden her anymore. I went to the centre [disabled people's institution] alone, I called the DSW and they arranged a transport for me to go to the centre. Since then I never returned home […]

After completing her training at the disabled people's institution, she took several posts of employment before running a small business from home. She married a disabled man and has never communicated with any of her family members since she left home. However this complete break with family members was, and remained, very upsetting for Dilah. Here it was important to observe that her level of impairment played a significant role in helping her to be independent. As an amputee she had the advantage in that she was able to move around using crutches (despite significant structural barriers in Malaysia) and did not have to rely on a wheelchair; unlike those who had paralysis or had to rely on other people in the case of severe impairment. However if she had not been able to be independent, because of her type of impairment, and in the absence of a welfare state, she would have had no family to fall back on. Therefore her level of impairment played a significant role in helping her become independent from her family support. Thus sometimes even without adequate family support, some of the women were able to gain autonomy and lead an independent life.

Similarly Eryna, who was receiving less physical and emotional support from her family, disclosed:

> [...] I am not close to my family. I don't know, perhaps my family is a fierce family. My brother is fierce, so since I was small, he used to beat me - but it was to teach me [...] I respect my father although he never wanted to communicate with me as he is like a man. But my mother always beat me even after I became disabled, she pushed me

> asking me to walk. I couldn't walk. She loves me but maybe the way she loves me is different.

Whilst Eryna was treated with harshness in the family, it did not prevent her from developing her ability to become an independent being without their strong emotional support:

> […] I have a woman's heart; I need someone to talk to. I cannot talk to my brother about my problems. I don't have anyone to express my emotions to. I don't have friends who I can share my feelings with. My sister lives far from home and is much older than me. I have no one at the moment. So I have learned to think by myself, that's why when I fall sick, I never tell my family, I used to get things sorted out by myself [...] I used to keep many things from my family.

Therefore at the age of 18, like Dilah, Eryna registered herself at a vocational centre for disabled people although her parents strongly disagreed with her decision (this will be discussed again in section 5.4.2). After completing her vocational training, she pursued her studies to higher levels until she managed to secure good employment and lived alone - far from her family and hometown. She then married a disabled man and they had a child. In this case it was possible for some of the women to use the institutional support provided by the state and eventually lead an independent life. Thus in some situations, for certain women, the lack of family support could empower them to be independent in their lives.

5.4 Gender roles and gender divisions within family

While Malaysia has undergone rapid socio-economic growth following its independence, little has changed with respect to gender equality and strong traditional values regarding traditional gender roles and gender divisions still predominate within society. Women in Malaysia are almost always associated with the primary roles of engaging with the family, marriage and children and are therefore constrained within their homes; fulfilling the basic functions of wives and mothers, such as cooking and caring for the household (Yun, 1984; NGO Shadow Report Group, 2005; Aminah, 1998). Whilst women increasingly are entering the workforce, their primary role is still in the home and men are still 'the head of the household and one step above the women' (Noraini, 1999: 125). As such the women's status is perceived to be 'lower' than men and this is true across the different ethnic groups of Malay, Chinese and Indian (Noraini, 1999). In addition many Malaysian families still practise the authoritarian style of bringing up children, where the rationale for restrictions is that they are for the ‘protection’ of the girl and the authority of the father is not to be questioned (Rohana, 1997:77). Men are thus viewed as ‘protectors’ of women, parents have to be respected and their opinions are highly valued.

This section therefore will discuss how the women interviewed experienced such traditional gender roles within their family and how this influenced their lives. It was observed that for the majority of participants’ families, the women became the primary carers and men became the dominant figures. Such strong traditional gender roles and gender divisions within family influenced how the participants received inter-familial support and how the women themselves subscribed to such gender roles and felt ‘disempowered’ when they ‘failed’ to perform such roles; as this section will show.

5.4.1 Women as the primary carer

The majority of women described how their mothers played the key role in providing care in the family. Many of them had a very strong bond and attachment with their mother because they spent a lot of time with them as compared to their fathers. The act of providing care, which becomes a routine between the mother and disabled daughter, creates a relationship of ‘a caring nexus’ that is defined by Morgan as:

> […] both constituted by and constituting the ideas of family and gender. Thus, women may be found to be engaging in caring practices within the home and elsewhere, but it is also the case that the identities of women and gender are constructed and shaped within the caring process (Morgan, 1996: 111).

For some feminists ‘caring is the central process through which gender is defined’ (Hughes et al., 2005: 261). Likewise Graham (1983) suggests that caring is always identified with ‘femaleness’ and that a woman’s identity develops through a caring relationship. As Watson et al., suggest:

> Caring work is often assumed and silently demanded from mothers and women more generally. Most meet these demands, embracing them in an active fashion, as demonstrations of their femininity and presumed social and economic roles (Watson et al., 2004: 333).

As can be observed in the above sections, the mothers and sisters provided key support to disabled family members in the absence of the welfare state. The participants learnt their gender roles as carer within the family from their caring relationship with their mother and sisters. Therefore many women, regardless of ethnicity, subscribed to such roles and became the primary carer in their family by helping their mother and siblings to look after other non-disabled family members such as their nephews and nieces, as the following examples demonstrate:

> When my mum went to the estate, I would look after my nephews and nieces because my brother and his family stay with us. I look after them while sewing clothes ordered by customers (Prema)
>
> I used to help my mum look after my brother's children at home. When my mum wanted to go out, she left them with me. I can shower them, clean their nappies, put on their clothes and everything (Ika)
>
> After I quit school, I used to help my mother look after my nephews and nieces. Sometimes, I stayed at their home to look after them when their parents went to work (Farah)

The examples above clearly describe how these women learnt from their mother to become the carer in the family and this was supported by the interdependent nature of many Malaysian families. Their impairment thus did not prevent them from fulfilling their expected caring role within their family. Moreover for the families with several disabled family members it was observed that mother still became the primary carer. For example Cornie Tan vividly expressed how her mother played a central role in providing care in her family which had a number of disabled members:

> My mother didn't see my father differently although he had an impairment. She accepts him as her husband even though he is weak. At that time I know that my mother was really tired because I understand how my mum feels. It was so hard because I have seven siblings and six of us have an impairment inherited from my father. She had to look after all of us. At the same time she had to work outside the home and had to come back to cook and take care of us [...]

Farah also disclosed her experience of how her mother looked after her family, which had two members with impairments. She felt sorry for her mother and felt that the load that she carried was great. She also felt unable to fully share her problems with her, although she wanted to:

> Sometimes, I told my problems to my sister but not always, because she was already married and had her own family. I rarely told my problems to my mum because I didn't want to make her worry because she also looked after my older sister who is also disabled.

Without a welfare state it was often the mother who had to pick up the caring duties. Likewise Nani also built up her own fortitude because she did not want to burden her mother who was alone in providing care for her two disabled brothers after her father passed away a year earlier:

> After my father passed away, my mother was alone at home looking after my brothers. It was like one of my mother's wings had been broken so it was hard to fly. As a daughter I have to be mature, I need to give moral support for my mum. If I am not OK then how will my mother be fine? She would not show her sadness in front of her children, I knew that [...]

The three examples above exhibit how the mother became the primary carer in a family with several disabled members. Similarly Shah and Priestley in their study on disabled people in the UK found that, 'irrespective of the presence of fathers in the family household, mothers usually took responsibility for the health and welfare of their disabled children' (2011: 49). The mothers provided care and love to their disabled children without compromising despite their emotional and physical fatigue. This 'care role' was then subscribed to by the women themselves as they saw their mothers as a living example for them. These women learnt from their mothers that as a woman they had to be strong and it was their responsibility to look after their family members, to love and care for them, especially those with impairments.

This was displayed by Nani (as discussed above), who helped her mother look after one of her disabled brothers who studied at the same place as her. As she described:

> My daily routine [at the university accommodation] starts with taking care of my brother. I will see if he needs to take a bath then I will help him take a shower and then help him get dressed.

Despite her impairment Nani could also provide care and support to her disabled brother and thus exercised her agency within her family. Therefore the traditional gender role that portrays women as the primary carer in the family was evident in many families, regardless of ethnic groups, and this was more apparent in the absence of the welfare state.

5.4.2 'I want to be like other women too!'

Women, as previously argued, were predominantly regarded as the primary carer in a family and it was their obligation to serve the family. Many women in this study observed, and learned from, their mothers and sisters that, as a woman, they had to be able to cook, to clean the house, and to look after the family. It was a mutual understanding in their families that women played a key role in doing household chores. In this section it will be shown how some women felt upset because they were not allowed to perform the normal traditional gender roles expected from a female member of the family.

Azni, who was born with an impairment, expressed her frustration at her mother's attitude which restricted her from exercising her ability to do household tasks:

> I know that my mum loves me but sometimes I am angry at her because she never allows me to do many things. She keeps asking me to read books. She never allows me to do cooking, washing clothes and even washing my plates. Whenever she needs helps in the kitchen she always calls my younger sister but not me. I felt so stressed out and pressured! I told her 'if you never allow me to do anything then what will happen when you are no longer alive?' One day, my older sister was giving birth. My mum went to her house to look after her and her baby. Then I took the opportunity to look after our house. I did everything from cooking, washing clothes and plates. I felt so happy and content. When she came back, she was surprised that I did all those things. Then she knew that I am capable of doing household chores, not only reading books. *It made me fed up as I want to be like other women too!* (emphasis added).

Whilst Azni's mother saw her impairment as an obstacle to her functioning as a woman, Huifang was prevented by the inaccessibility of her family's home:

> I didn't feel happy at home. I felt isolated compared to my siblings. They could do many things which I couldn't. I couldn't even cook because we had no facilities for me [to do that]. My home at that time had a charcoal wooden kitchen. So I couldn't use it. All I could do was helping my mum wash clothes, that's all. You know, we lived in an estate house. [There were] no facilities at all for me. Deep in my heart I really wanted to help my mum because I wanted to be like a normal girl too, like my sisters, but I couldn't.

Therefore these women felt forbidden from realising their 'womanhood': a result of significant attitudinal and structural barriers within their familial environment. In another example, the ability to perform traditional woman's roles is seen as the ability to be independent, as expressed by Nadia:

> My father loved me but it was my mother who played the central role. Like for example, if I was at home, my father never allowed me do the household tasks like sweeping the floor, cooking and washing clothes. He loved me so much that he did not teach me to be independent. Unlike my mum: she asked me to sweep the floor even [if] I [needed to] crawl on the floor while doing it. I did not use a wheelchair. I even took my own meals from the kitchen although the kitchen was quite high for me. My mum wanted to teach me to be independent.

Household chores not only symbolised 'womanhood' but were also associated with the ability to be independent for Nadia and her mother. This reiterated the previous theme that associated the inability to do household tasks with becoming too dependent in the family; for example as experienced by Alice Chong and Nisa (see 5.3.3); a reinforcement of their dependency. Although within feminist literature it may be seen as oppressive to associate women with household chores, the ability to perform traditional woman's roles within the family was culturally pivotal for these women. They not only felt 'disadvantaged' because they had to succumb to the traditional women's roles, but they felt 'disempowered' by not being able to perform such roles. Therefore it suggests that disabled women in Malaysia may experience complex disability experiences observing dynamic interactions between impairment, gender roles, culture, environmental and attitudinal barriers in their family.

5.4.3 Gender and power

In the above section it was discussed how women were strongly identified with the caring roles and thus it was suggested that the absence of the welfare state reinforced the inequality in the allocation of caring tasks within a family. Despite physical and emotional fatigue women continued to provide primary care. It was observed that within many Malaysian families, especially those with disabled family members, there were strong gender divisions and power relations between men and women. This section will explore how men were accorded as 'dominant figures' in the family and held more power and control over female members. These gender inequalities exposed some of the women to significant power control and exploitation by male family members that restricted their agency and opportunity to be included in the family.

As discussed earlier, many Malaysian families still practise the authoritarian parenting style and the father has the highest authority in the family while male family members act as 'protectors' to female members (Rohana, 1997). Whilst this is accepted within Malaysian families as 'caring virtue', such a type of caring relationship tends to be problematic for some women. For which Sevenhuijsen argues:

> Even if care is to a certain extent generated by dependency and attentiveness, the concrete motives in social practices of care cannot always be derived from the urge to protect dependent people from vulnerability. Caring for others can also stem from less noble motives, such as the urge to meddle or to control others (Sevenhuijsen, 1998: 20).

'The shadow side of virtue', as defined by Sevenhuijsen (1998: 12), in a caring relationship could expose disabled daughters to the dangers of control and exploitation by male family members. For instance Nadia disclosed how she had to struggle to get her father's permission to study in a vocational centre for disabled people:

> After the SPM [high school] I applied to a rehabilitation centre for disabled people. But my father would not give his permission. You know that we lived in a village; he worried that villagers would talk badly about him. Well, people might think that because I am 'handicapped', he sent me to a 'welfare home' […] Then I went on a

> hunger strike for three days. After three days he allowed me to go there.

It is interesting that despite such greater control from her father, Nadia was able to challenge such domination within her patriarchal family and exercised her agency as an independent social actor. However this was not without cost as she had to deal with strong resistance from her father and had to formulate extreme strategies to win his approval. This episode showed that providing care and ‘over-protection’ to disabled daughters did not always work for all women. They wanted to prove that they were capable and independent social agents in their family. Therefore it is important to understand these women’s view of their aspirations in life as ‘what is important to children may not be seen as important to adults and *vice versa*’ (Watson, 2012b: 199).

The dominating role and strong control not only came from the father but also from other male figures in the family such as brothers. For example Ainul told how she got into difficulties because of her eldest brother. After the death of her parents, her eldest brother became the ‘dominant figure’ in the family. All decisions in her family were determined by her eldest brother as he was the most senior male member in the family. Because of this strong gender division in her family she came into constant conflict regarding access to her late parents’ house. As a wheelchair user, Ainul vividly expressed how she was upset with the attitude of her eldest brother towards her:

> After my parents passed away, my eldest brother played a key role among our siblings. We had several discussions but, in the end, we never agreed to use my late parents’ money to make renovations in our family house [because it was not accessible to her]. Although my parents had discussed this with us while they were still alive, my eldest brother was the one who strongly objected to this plan. He said that they [her siblings] wanted to use the money because they also had some problems. I just kept quiet but only God knows how hurt I was. Since then, I have rarely been back to our family home […]

As a female member of the family Ainul had less power than her brothers - especially her eldest brother - and this made her vulnerable and unable to challenge his wishes. It is a common practice in Malaysia for sons to have more of a voice in the family. Females remain in second position after the male figures in a family (Noraini, 1999) and Malaysian women are constrained by the Asian discourse that promotes a very strict prescription of female behaviour and roles (Ng et al., 2006). Consequently Ainul was unable to take part in many family activities and play her roles in the family because her wheelchair was ‘not welcome’ in her family’s house and her position as a daughter prevented her from voicing her opinion. This hierarchical relation of power between male and female family members tends to disadvantage women and preventing gender equality. It thus shows a dynamic intersection between disablism and gender that made disabled women felt ‘disadvantaged’ not only because of their disability, but also because of their gender position.

5.5 Conclusion

This chapter observed how family played crucial roles in supporting women with impairment in many aspects of their lives in the absence of strong welfare state. This reinforced high dependency on family as the primary care and thus encouraged interdependency amongst family members of disabled women. Nevertheless in some cases where there was a lack of support provided by the family the women turned to institutional support offered by the state; however inadequate.

It was revealed that impairment, poverty, rurality, attitudinal and structural barriers, gender and cultural norms had a significant impact on how those women experienced their lives and how these factors influenced their familial relationships. All these worked together and posed challenges to these women in receiving and providing care within the family and during the process of negotiating their identity within the family. Whilst the negative attitudes of the family towards disabled women significantly undermined their sense of self, causing them to experience ‘psycho-emotional disablism’ as proposed by Thomas (1999; 2007) and Reeve (2008; 2012), it is important to note that their impairment, functional limitations, socio-economic conditions, gender and cultural norms also had pivotal effects on them and their family.

Therefore an understanding of the disability experience within the dynamic of these familial relationships needs to be understood beyond the parameters of structural and attitudinal barriers. Rather it should include a complex analysis of the disability phenomenon. The disability analysis should be able to interrogate different contexts, meanings and experiences, as described by the research participants; thus presenting their lives’ experiences from their point of views.

Chapter 6: Love, Marriage and Motherhood

6.1 Introduction

The preceding chapter showed how the lack of support from the welfare state, reinforced by a strong dependency on family, created barriers for many of the women. The majority of the women interviewed described how their family provided primary care for them despite significant conflicts and challenges produced within the family. Gender related issues still dominated these women's experiences within their familial environment and interactions. It was revealed that many women subscribed to traditional gender roles within their family and some of them felt restricted in exercising their agency as women and individuals because of their impairment and power relations in the family.

This chapter will explore how the women sought (or not) to have a romantic relationship and how they experienced love, marriage and motherhood. There was a fairly even split in the relationship status of the women interviewed. Of the 33 women single and married women were divided equally (14), while the remaining participants were either in a relationship (3), co-habiting (1), or divorced (1). Eight of the married women had children; the other six did not. The divorcee was the only woman not in a relationship to have children. Ethnicity also seemed to affect marital status: the majority of Chinese participants were married, while only two of the Indian women were; and there was an even divide between married and unmarried Malay women. The majority of women with an acquired impairment got married after they became disabled and most of them were married to disabled men rather than non-disabled men. This chapter will discuss how these women faced significant barriers to realising their right to have relationships and families within Malaysian society.

6.2 Love, marriage and motherhood

6.2.1 Loneliness and isolation

As discussed in Chapter 1, having a family is regarded as one of the most basic fundamentals in the lives of most Malaysians; especially women (Noraini, 1999; Joseph, 2000). Chapter 4 and 5 continued to display scenarios in which family was seen to play a central role in supporting the majority of participants. The interdependent relationships and solidarity exhibited by the family members, albeit inadequate for some women, taught them that having a family was pivotal to their identities. This section therefore will portray how many women expressed their wish to have a partner and often felt lonesome and isolated because of this.

For example Rupa (Indian), who had entered her middle age, described her loneliness and fear of being single:

> [...] My mum is already old, so how long am I going to be alone? But what can I do? I can’t find a man who really understands me […]

As found in the previous chapter, mothers tended to become the primary carer for disabled daughters. In this case Rupa’s mother provided affective love and psycho-emotional support for her as they lived together. Rupa was concerned with the possibility of losing her mother and thus being left all alone. Consequently this created pressure for her to develop a romantic relationship with a man in her search for emotional partnership.

Likewise Jiaying (Chinese) expressed her feelings of loneliness when comparing herself with her other family members:

> I want to get married. I see my siblings are happy with their own families but I am alone. Almost every night I feel lonely. I was thinking about myself […]

In Malaysia, despite a significant change in marriage patterns since the 1940s that have seen an increase in the age at which people get married (see Tey, 2007), the majority of population still opt for marriage. For instance until 2010, almost 60 percent of the total population (aged 15 years and above) were married and the mean age of first marriages for females was 25.7 years; with males at 28.0 years (Department of Statistics Malaysia, 2011). Therefore many women in this study who were no longer in their 20s, voiced their concerns about getting married as it was, in contrast to the West, against Malaysian norms to remain single at a later age (Abdul Aziz, 2001: 39). As Ainul (Malay) described:

> I really want to get married as my age is now already 40. I really wish to, really wish to get married.

Besides, these women subscribed to the traditional gender roles within the family that expected them to look after the family and to be restricted to domestic chores:

> I want to have my own family. I want to look after my husband, I want to cook, managing the house and taking care of my children like other women do (Nora, Indian).

These women felt isolated compared to other women who were able to perform traditional roles as wives and mothers, as articulated by Ika (Malay):

> I am a woman, you know [...] If God wills, I want to have my own child because when I stayed at home with my mum, I used to look after my nieces and nephews. My mother looked after them since they were born. So my mum always leaves them with me.

Ika's experience of taking care of babies in her family (her siblings' children) empowered her to become a mother and have her own children. She learned the traditional roles of being a woman and a carer within her home environment, from her mother, a common experience shared by many other participants (see Chapter 5, 5.4.1). As such many single women felt helpless when their hope of becoming a mother was not realised:

> I really want to have my own child. That is my only hope but you know that sometimes what we really wish will not come true (Ainul).

The aspiration to have partners and become wives and mothers was vital for many of the women across different ethnic groups of Malay, Chinese and Indian. Barriers to these gender roles and expectations could therefore significantly impact on their psycho-emotional wellbeing as this chapter will explore later.

6.2.2 Intimacy

In Malaysian culture issues related to intimacy, such as sex or physical relationships, are not discussed openly, and are often only disclosed to traditional healers or discussed between spouses in the privacy of the bedroom (Aiza Shafrina and Engkasan, 2011). Sexual issues are seen as a taboo subject and ones that should be avoided in public discussion given that the subject has a strong association to cultural and religious sensitivities (Ng et al., 2006). Consequently these social norms restricted an in-depth exploration of this theme - if the discussion of sexual issues took place during the interviews, it had to be treated carefully. For example it was culturally incorrect to ask non-married women about intimacy issues as they may have felt offended. Also with married women; discussions about sex related issues could only take place with caution and if they were open towards it. Despite these cultural and religious limitations a few of the women, especially Indian participants, felt able to discuss their sexual experiences as this section discloses.

It has been argued that in the Global North people have negative attitudes towards disabled people's sexuality as they were seen as asexual beings that are neither desirable, nor desirous of sexual activities (Shakespeare et al., 1996; Milligan and Neufeldt, 2001; Shakespeare, 2014); this is especially true for disabled women (Finger, 1984; Morris, 1989, Lonsdale; Begum, 1992; Waxman-Fidduccia, 1999; Garland-Thomson, 2002; Malacrida, 2009). However previous studies suggested that sexual satisfaction and body-esteem are important for the wellbeing of those with physical impairments (see, for example, Shakespeare et al., 1996, Shuttleworth, 2000, Taleporos, 2001; Taleporos and McCabe, 2002a). For example a study on women with spinal cord injury in Malaysia found that, despite a decline in the frequency of sexual activity, 40 percent of them continued to have sexual intercourse after their injury (Aiza Shafrina and Patrick Engkasan, 2011). It thus showed that women with impairment are not asexual beings and sexual intimacy is important for them.

Similar feelings were expressed by some from this sample for example, Deepa who had previously had an intimate relationship with a married man:

> It was good while it [their relationship] lasted for 12 years. At least I feel, I didn't know I [could] feel like a complete woman. We were intimate because I know I'm not going to get married. I mean like [you] because for Muslims of course that is not allowed. Not encouraged. I'm a Hindu. Yea, so it is [on] my conscience. It was between me and God. I mean I take it like that [...] I feel more complete. I mean having had sexual experiences and that means the joy of it. He did compare his able bodied wife to me you know. He was my first love. That's the reason why I couldn't get close to anyone else although some men were interested in me[14].

The above extract illustrates that women with impairment undeniably have sexual desires and having sexual experiences reinforced a positive aspect of their identity. Deepa's sexual experiences thus gave her a positive attitude towards her impaired female body that made her felt like a 'complete woman'. This aspect of positive body-esteem is crucial for disabled women as Taleporos and McCabe (2002b) found that body-esteem had strong relation with self-esteem amongst women with impairment.

In addition, intimacy was not only about sexual satisfaction but also about companionship. Pushpa, who married a disabled man, related:

> Marriage is not all sexuality you know. The important thing is your companion, somebody who must understand you. We are quite outspoken about sexuality. My husband even asked me 'do you still have menstruation?' [...] Then he asked 'what the sensation is like, where do you feel and where you do not'. So we learn on our own, we develop ourselves you see. Then he also tells me that he also has sensations. Even hugging your partner is also loving already. Not necessarily to have sex right? [...] So far I have been married for the past 6-7 years already. I have no problem, I am very happy!

Whilst sexual issues are not discussed openly in Malaysia, and only a few of the women talked about it, intimate experiences which involve physical relationships with their partners are often important for women with impairment. However in Malaysia, where Islam is the official religion of the state and the majority of population are Muslims, there may be differences among participants in their sexual experiences. For Muslim women their religion prohibits physical contact or sexual intercourse between men and women before marriage. Therefore it

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[14] A partial of this quotation was used in Chapter 3 (see 3.3.5) to demonstrate the cultural and religious difference between this participant and the researcher. However both quotes have been used in different contexts.

suggests that single Muslim women may be restricted from having sexual activities; not only because of their disability but also due to their religious beliefs.

6.2.3 Financial exploitation

Many of the women described how they had experienced manipulative love relationships with both disabled and non-disabled men. These women expressed their frustration when their hope for a romantic relationship was exploited and betrayed. For example Alice Chong was extremely upset when her long dating (non-disabled) partner married another woman despite her giving him money:

> **Alice Chong:** He's the only one, he is the first and the last. I don't want that guy anymore. Now I want to focus on my work [...] previously all my money went to this guy *lah*
>
> **Me:** Em...that's means he took money from you?
>
> **Alice Chong:** Ya that's why I said I don't know whether he is taking advantage of me or playing with me. I don't know. That's why I no longer trust any men. Especially for disabled girls, we can't trust men. I always advise them [disabled women] to be extra careful and not to trust men just like that. I feel that I have been frustrated with him so many times. Now I really can't trust any guy anymore [...] Until now he never said he doesn't like me or he doesn't love me or he never say anything [like that] he just played behind me [and] then got married with other girl.
>
> **Me:** Em...without telling you?
>
> **Alice Chong:** Yes without telling me!

Alice Chong felt more frustrated when the man kept asking money from her even after he got married:

> But what made me feel very hurt was that after he got married with that girl he still came and asked me money [...] that's why until now I told him that I'm very sorry I'm not a bank! So I said to him I don't want to feel pity for him anymore. I want to carry on with my life. I want to pay attention more to my mother, give her more love [...] it's hard to be disabled. I can say that my life is awful. I also want to be normal like everyone else you know, having a family, having children, to be loved by someone. But I don't know; maybe not for me. I don't know, maybe disabled women like me cannot have their own life like that (crying) I really sincere with him but I don't know *lah*. Maybe he was taking

> advantage or maybe he just wanted my money (crying). So I think my life is very terrible *lah*.

Consequently she decided to end the manipulative relationship as she added:

> **Alice Chong:** I feel very stupid. When he had a problem he came and asked for money from me. I felt sorry for him and gave him money. By rights I should not give him money anymore. So I told myself this was the last time I would give him money.
>
> **Me:** When was the last time you gave him money?
>
> **Alice Chong:** Just 2 weeks ago. That's why I feel I am very stupid [...] I have to be very strong!

Despite her realisation, Alice Chong felt too ‘powerless’ to leave such an abusive relationship. On the other hand Zahra felt empowered by her past experience:

> I was in love with a disabled man here [a sheltered workshop for disabled people] for 6 years. All my savings in the bank went to that man. He took advantage of me [...] I cannot hate him although he keeps asking me to return to him. But I refused [to be with him again] because I think about my family and my future. I was stupid last time but now I will not be that stupid again.

For these women their bad experience with men who exploited them financially left them feeling vulnerable in developing relationships with other men. Although some of them were able to ‘escape’ from such abusive relationships, it left them with long term psychological effects. It made them felt that they were ‘stupid’ and ‘helpless’ with men and thus it suggests that men had more ‘power’ over them.

6.3 Barriers to marriage and motherhood

Many of those interviewed expressed a wish to be part of loving relationships with a partner and hopefully with their own children. However many of them encountered significant individual, familial, and societal barriers as this section will show.

6.3.1 Individual constraints

It is important to note that barriers to marriage and motherhood were not only stemmed from external factors such as the family and society but also from intrinsic factors. Many women expressed their fear of forming romantic relationships with men because of several reasons: a negative attitude towards the self and body, a lack of confidence in their ability to perform women's traditional roles, and socio-economic issues.

Imah for example felt that she was not 'perfect' enough to be loved by non-disabled men because of her impairment:

> […] But deep in my heart I thought that I am not perfect, that's why I still don't have a boyfriend. If I was not disabled, I might have a steady boyfriend right now.

She also stated that she preferred to have a non-disabled partner because she thought that, as a disabled woman, she needed someone who was not disabled and could support her physically. However as someone with visible impairment she felt that she was not 'perfect' enough for such a relationship. The possibility of forming a relationship with non-disabled men made her aware of her body and thus it undermined her self-esteem. This can be linked to the work of Erving Goffman (1968) on *Stigma* that explores the experience of 'spoiled identity' (see Chapter 7 for detailed discussion on this). Imah was not only subjected to the societal stigma displayed towards disabled persons but she herself adopted it and stigmatised disabled men as being unable to meet her physical needs.

On the contrary Huifang not only perceived her impairment as a barrier to develop relationships with non-disabled men, but also with disabled men, as she said:

> There was a [disabled] man who came and looked for me where I used to work but I didn't feel I wanted to [accept him] because I felt too shy to talk to him. I felt that I am not perfect, I have an impairment, I felt that I was not beautiful, was I worthy of him or not […]

This suggests that women with physical impairments may have a distorted self-image because their body is seen as 'different' and not 'perfect' when perceived by society. These women were subjected to the societal conception of stereotypical images of women where great emphasis is placed on the 'beauty' of women's bodies (Morris, 1993). These women may have internalised the cultural values of physical attractiveness and would find that their physical appearance could not fulfil such stereotypes. As a result they suffered a distorted self-image as their physical appearance differed from societal norms (Lonsdale, 1990:65): feeding into their own feelings about their physical impairment.

In Malaysia, as elsewhere, the mass media reinforce a stereotyped image of women who should ideally be young, slim, and fair (All Women's Action Society [AWAM], 2003). The average Malaysian females are represented by beautiful women in many advertisements. Images of disabled women are rarely depicted in local television or films, and are almost absent in Malaysian society. Thus society may not be aware of how disabled women look, and it tends to have a universal image of women as 'beautiful', 'healthy' and 'able-bodied'. Therefore the women interviewed co-opted these social values as their own and developed low self-esteem since their bodies were not socially 'perfect'. In order to have a romantic relationship, they felt that they should be 'beautiful' and have a 'perfect' body as reinforced by society. As Cornie Tan uttered:

> I met my husband in this centre [a residential institute for disabled people] when I was studying in a college here. He came here as a volunteer to help at this centre […] When he approached me for the first time, I could not believe that. It was really funny you know. I can't believe that he can accept me and my disability because my impairment is getting worse day by day. Now, I still can walk but maybe in 10 years' time I will not be able to walk and I will have to use a wheelchair […] But he did not give up. He continuously convinced me for almost 2 years. Only then, I accepted his love proposal.

The above extract reinforces the idea of that women with physical impairment internalised the societal stigma towards them and perceived themselves as having a 'spoiled identity' not worthy for non-disabled men: this was supported by Amanda Chan:

> I got married to my husband after he was involved in an accident [...] If I was given a choice, I would not marry an able-bodied person [...] I see so many disabled people - a lot of my friends are married [to non-disabled partners] you know, the first two years [they] would be very

> happy. But after a while, [their] husband [would then] find another able-bodied woman. You see too many cases. This warned me to be cautious. Last time, I had a relationship with an able-bodied man, but I put a stop to it. I refused to proceed. I didn’t want to get myself too involved because I didn't want myself to get hurt.

As such the findings suggested that disabled women (spoiled identity) should only marry disabled men (spoiled identity). This notion of a spoiled identity will be discussed in more detail in Chapter 7. These women also might have lack of confidence in performing women’s traditional roles in the family. As discussed earlier (see Chapter 1 and 5) many women subscribed to the traditional gender roles within family where domestic tasks are assigned to them. Consequently some women felt that their physical impairment would restrict them from performing their roles as wives at home, as expressed by Prema:

> For me it is better for disabled women to get married to disabled men because only disabled people will understand us, right? Like me, I am married to a disabled man. Let’s say I got married to a non-disabled man, maybe he would not understand me. Like for example, as a disabled person, we cannot do [household] jobs like a non-disabled person. So, if I can’t clean my house properly, my husband will not get angry because he is also disabled […] I observe many of my friends who get married to non-disabled men - after a few years they have marriage problems.

Therefore such a marital relationship that involved ‘shared spoiled identities’ between disabled women and disabled men was assumed to have less conflict in the fulfilment of the expected gender roles and gender divisions within family. Conversely some women did not have negative attitudes towards their own abilities to perform women’s roles but they had negative attitudes towards both disabled and non-disabled men because of their socio-economic status. Women with a higher education and financial status felt that men from a lower socio-economic class than them could not be trusted, as Rupa said:

> […] it’s not that no man has approached me. There were some disabled men interested in me, but I don’t really like them because some of them don’t even have a job. So I am afraid whether they like me because I have worked for so long or because I am disabled or what? I’m afraid that I’ll have to financially support him because I already have a house, a car […] but then it’s not that I don’t want to get married, but I want to find someone who can look after me. But no able-bodied man is interested in me - just disabled men who are financially unstable. (Pause) Sorry I can’t help myself when talking

> about this (crying).

Moreover Murni felt that her status was higher than uneducated men:

> Well, if you are an educated woman, even if you are not disabled, you don't have many opportunities to choose someone who is compatible with you. I found many of my friends, including those who are not disabled, have difficulty finding marriage partners. Those that are suitable and who won't abuse. I mean abuse financially. They earn less than you. At the end of the day, you are going to be the leader. Financially both are not compatible. Then you will suffer, right? So what's the point of getting married if you will only suffer?

Discussion here therefore suggests that the pertinent issue present was more than just about disability; it was linked to social class and the possibility of securing prospective partners that met their standards. Furthermore it was also related to the strong gender roles and gender divisions within Malaysian society that assigns men as the breadwinners of the family (see Chapter 1, 1.4.4). As such men were expected to earn more than women and it was unlikely for women to marry those with a lower income than them. Also these women might had negative perceptions of men with low economic status because they learnt from other women's experiences of being financially abused by their partners; as Murni mentioned above and as discussed earlier in 6.2.3. Hence the interviews disclosed several issues involving women's choices and prospects of marriage, revealing a complex interaction between the intrinsic aspects and contextual factors.

In addition to individual barriers to relationships and marriage, some women were denied a parenting role because of fertility issues and the fear of having a disabled child; as well as a lack of confidence in their ability to become an 'ideal' mother. A desire for motherhood was common, although for some the financial demands of IVF meant that this was unlikely:

> I really wanted to have a child but it has not happened yet. I went to see a doctor to consider the IVF procedure but I need to prepare about RM15,000 to RM20,000. I can't afford it and there is no guarantee that it will work. So, what can I do? I really want to have my own child, I really want it. I want to know how it feels to be a mother (Cuifen).

Although Cuifen could have considered medical procedures to help her become pregnant, financial constraints hindered her. The lack of financial support from the welfare state, and her low economic status, restricted her opportunity to become a mother. This significantly undermined her wellbeing; she further added:

> When I see other women become pregnant, like my friends who are already pregnant with their first and even second child, I feel upset because I myself can't be a mother yet. 'When will I become a mother?' That is what I always ask my husband.

The inability to become mothers not only resulted from fertility issues but it may also have been contributed to by the women's fear of having a disabled child because they inherited their impairment from their parent(s):

> I was scared when I became pregnant for the first time because I knew that we inherited this disease from my father. I don't know how I could accept it if my child also had the same condition like me [...] But then, my husband encouraged and supported me. He said to leave it to God and accept whatever God gives us. At the same time, I was afraid because my older sister [who has the same condition as her] encountered many problems during her pregnancy and she nearly lost her life. We were really scared that she would pass away at that time. So, I was afraid that I would also experience that (Cornie Tan)[15].

Similarly Lijuan also shared her fears about her pregnancy:

> I was scared when I became pregnant. You know that I have this disease and all my siblings also got this from our parents. So we discussed it with the doctor and he said that if my husband was 'normal' then my baby would not get this disease. I was quite relieved knowing that but still worried whether one day my daughter will develop the same symptoms as me.

The fear that these women had on their inherited impairment condition did not only psychologically affected married women but also single women:

> I am happy to see other women get pregnant because I want to experience that too but when I think about it I feel scared. I'm afraid of whether my child will also get the same disease as me. I don't dare

---

[15] Cornie Tan was able to overcome her anxiety to have her own baby and with strong support from her husband they subsequently had two non-disabled children.

> to see my baby suffering like me (Nora)

Nora's health concerns were so dominant that it made her reluctant to have a disabled child, one who might in turn go through the same experiences as her mother. It is crucial to note that these women were not only fearful that their children might inherit their impairment but what most important was that they did not want their children to be stigmatised in society, as Cornie Tan mentioned:

> I was so worried [that I will give birth to a disabled baby] because I didn't want my child to experience life like I did – I was bullied by people since I was a kid.

This indicates that it was not the impairment that prevented her from considering having her own baby, but rather it was the societal reaction to it that restricted her. Her traumatic childhood experience of living with impairment and the negative attitudes that people had towards her became a major obstacle to her becoming a mother. Likewise another woman, Wei Yin, was not only afraid that she might have a disabled child but she also internalised the societal stigma regarding her ability to become a mother because she had no idea how to look after children with her physical impairment:

> I met him [her partner] 10 years ago. He was separated from his wife at that time. They did not divorce but were just separated. They have 2 children. So I don't want to get married to him because I don't want to have children. Although I know that Polio cannot be inherited, I am worried. How could I bathe my baby when I cannot bend my legs? So how can I do that - it's not possible, right? He said that he could bathe our baby and hire a maid but I said I don't want that. I told him if he wants me, we can stay together but I don't want to get married and want no children. That's my condition [to him]. So now, we have lived together [without getting married] for 10 years.

6.3.2 Familial control

As discussed earlier, the role of family in Malaysia exerts a great deal of control in the lives of many women. This section will examine how women were subjected to the control of their prospective partner's family, and their own family, when getting married to their partners. The participants provided various examples of how this control manifested.

Many women revealed that they were ‘rejected’ by the family of their non-disabled partners when becoming their daughter in law. This pattern of familial rejection was common amongst all ethnic groups. For example Nisa (Malay) described how her partner’s mother refused to accept her when she and her partner planned to get married. Although her partner’s mother knew that she had an impairment she never objected to their relationship, until, however, they decided to get married:

> I broke up with him in 2010 after 5 years of us being together [...] his mother dislikes me. Before that she was OK. I tried to figure out why this happened. Then, I came to realise that his mother had a prospective wife for him [...] Yes, a ‘perfect’ candidate, a ‘normal’ woman not a disabled woman like me.

Whereas for Lijuan (Chinese) her partner’s parents refused to accept her from the beginning of their relationship:

> At the beginning of our relationship, his parents disliked me. They refused to accept me because I am disabled. I was upset because I thought we would never get married. And then slowly after that they accepted me. So since then, they have accepted me the way I am.

However Deepa (Indian) never had opportunity to marry her partner due to his mother’s vehement denial:

> And the first time he [her first love] saw me disabled after my accident you know. And he cried and cried, and that time he was about to be engaged [it was his] family match. Yes, match made. So he said somehow he’d go back and convince his mother. He said he would try and he didn’t want to go through with the engagement. His mother didn’t agree and she said that she would commit suicide [if her partner married her]. It was just like a Tamil movie [...] I said [to him] never mind, you go ahead and you marry her.

Early in the 20th century, it was common practice in many Malaysian families - especially Indian and Malay families - to plan an ‘arranged marriage’ for their children. However this has become less common in recent times (Tan and Jones, 1990: 188). Although the prevalence of arranged marriage has declined over time, it remains an important facet of Malaysian life. Deepa was thus unable to proceed with her relationship and has remained single since then. Her ex-partner subsequently married a non-disabled woman who was suggested by his mother. Whilst many women across different ethnic groups were refused marriage to non-disabled men, some women were also rejected by disabled men's families. As Ainul described:

> My ex-boyfriend is also a disabled man but he is not in a wheelchair, like me. His parents strongly objected to our marriage plans because they wanted him to marry a non-disabled woman.

This type of familial rejection may have been linked to the strong traditional gender roles of women in Malaysia as primary carers in their families as discussed above. These women with visible impairments may have been perceived as incapable of fulfilling their basic functions of wives and mothers; such as cooking and caring for the home (NGO Shadow Report Group, 2005; Aminah Ahmad, 1998). Due to the limited participation of disabled people in society, reinforced by the poor exposure of disabled persons in the mainstream media, many Malaysians have little understanding of the abilities of disabled women when performing females' roles. Therefore many parents of both non-disabled and disabled men were reluctant to accept these women as their daughters-in-law and as such restricted their prospects of marriage and motherhood.

Nevertheless some women disclosed that their family exerted greater control on their choice of spouse too. For instance Azni (Malay) described how her mother strongly objected her plan to accept a marriage proposal from a non-disabled man:

> I had many male friends. They liked me and there was one guy who was really serious about me. But my mother said 'I am not saying that I don't allow you to be with him but he is normal and you are handicapped'. I am afraid that one day he will change his heart and leave you'. I was angry when my mother said that to me, but then when I gave it deep thought, maybe my mother was right. Maybe one day in the future he would leave me because I am 'handicapped' right?

This echoed the findings in 6.3.1 revealing how some women perceived that disabled women should marry disabled men only and that the difference in disability status between spouses might lead to greater marital conflicts. This ‘misleading’ conception came from the family of these women and later the women internalised such an ‘oppressive’ idea and embraced it. Consequently Azni decided to not accept the non-disabled man and married a disabled man.

However for some women their family did not object to them getting married to non-disabled men, but to those who had similar impairment to their own. Prema (Indian) explained that her parents wanted her to get married to a man with better physical abilities than herself:

> I met my husband in a sports tournament for disabled people […] They [the family] asked why I wanted to get married to someone in a wheelchair though I can walk. I was so depressed at that time because I really loved him [...]

It showed that disabled men were also subjected to social stigma and misconception regarding their abilities to become husbands. This may be associated with the strong gender roles and gender divisions in Malaysia that viewed men as the protector of women and breadwinner of the family as discussed earlier. It indicates that the hierarchy of impairment also played an important role on how disabled women and men were perceived in their ability to become wives or husbands. In view of that there is a suggestion that individuals with severe impairment may be more ‘disadvantaged’ than those with reduced level of impairment in their marriage prospect.

6.3.3 Sociocultural influences

Despite individual constraints and familial control many women deliberated how societal aspects influenced their marriage and motherhood prospects. These women experienced limited social interaction with men, especially non-disabled men, and likewise they were subjected to the powerful influences of cultural and religious values; as this section will reveal.

Their ability to meet new partners was very limited, mainly due to their poor access to wider social participation. Their lives were restricted to their homes or residential institutes for disabled people, and mostly involved their families and disabled colleagues. This left them with limited opportunities to meet non-disabled men. On top of that, these women were often exposed to a greater degree of control from their family as discussed above. It was not until they got away from the influence of their family that many of the research participants were able to form relationships, and many women met their prospective partner at vocational or training institutes for disabled people which may explain why the majority ended up relating to a disabled partner.

Women across the ethnic groups described how they met their husband or prospective partner either at disabled people's institutions, in activities involving disabled persons or through disabled peer support:

> I came to know my husband at X [a training institute for disabled people]. He was taking a tailoring course like me so we became close then (Intan, Malay)
>
> I met my husband in a sports tournament for disabled people in 2003. We got to know each other for about a year or more and got married after that (Cuifen, Chinese)
>
> When I had problems with my former employer, I asked for help from a disabled friend [now her husband]. He helped me a lot to deal with my problems. Then we became close and we got married a few years later after he divorced. Actually when I met him, he already had marital problems with his wife (Pushpa, Indian)

The above excerpts demonstrate how many of the women interviewed had more social exposure to disabled men than non-disabled men and eventually such limitations on their environment restricted their opportunities for wider marriage prospects.

While these women had few social interactions with non-disabled men, they were subjected to a greater influence from their cultural and religious principles as well. There were significant differences between ethnic/religious groups in their marriage prospects. A majority of the Malay-Muslim women would not proceed with their marriage plan if they encountered familial objections from either their own family or their prospective partner's family as compared to Chinese-Buddhist/Christian women and Indian-Hindu women.

Chinese and Indian women were more likely than the Malay-Muslim women to continue their marriage proposal with their partner despite strong opposition from their family or their partner's family.

For example a Chinese-Buddhist woman was able to marry her non-disabled partner although his father hardly accepted her:

> After 6 months of dating, he [her husband] brought me to meet his family. They all accepted me - except his father. His father wanted him to find a non-disabled woman. Although his father dislikes me, he can't do anything. We lived together for almost a year before we decided to get married. My husband said that it's better for us to get married than to cohabit (Huifang).

Similarly an Indian-Hindu woman, Prema (see 6.3.2), proceeded with her marriage proposal from her partner despite the strong wishes of her own family:

> [...] They [the family] asked why I wanted to get married to someone in a wheelchair though I can walk. I was so depressed at that time because I really loved him. I ran away from home and I went to my husband's hometown. So I got married at my husband's place [without her family's consent] because my family didn't allow me to marry him [...] After I got married I went back home and luckily my family was no longer angry at me. Fortunately my husband is kind otherwise I might have regretted it.

The above scenarios indicate that in spite of from the powerful influence of the family these women were able to resist by marrying those they loved: something that did not occur for Malay-Muslim women. For example Zahra a Malay-Muslim woman was unable to marry her partner due to the significant disapproval of her own family:

> I don't know how long we will be able to maintain this relationship. He is in his home country now. I still love him but my parents did not allow me to get married to him [...] he is non-Muslim and a foreigner so it's hard for them to accept him. So now we still keep in contact with each other and we promised to be loyal towards each other. I will try to convince my parents to accept him. We have given two years' time for us to get married with the blessing of my parents. I can only pray for the best for our relationship as I don't know if my parents will accept him. I am so helpless and disappointed as I don't know what else to do.

Likewise for another Malay-Muslim woman, Ainul was refused by her prospective partner's family (see 6.3.2), described how she had to wait for two years in order to get approval from his family:

> My ex-boyfriend is also a disabled man but he is not in a wheelchair, like me. His parents strongly objected to our marriage plans because they wanted him to marry a non-disabled woman. After his parents refused to accept me he still convinced me to proceed with our marriage plan. But he asked me to wait for him to convince his parents. At the beginning I felt hesitant but he firmly wanted to marry me. But then he is a son right: if he is getting married, he will strongly attach to his parents too. Then he moved to his hometown to live with his parents. We continued to have long distance relationship for a few months after. However as time went by we rarely contacted each other because we were busy with our own stuff. Now, for almost 2 years we have not been in contact and I have given up on our relationship.

The above cases suggest that Malay-Muslim women would not go against their family's wishes, or those of their prospective partner's family, in their marriage proposal. They chose to get parental approval either from their family's side or their prospective partner's family side before proceeding with marriage. This was significantly different from non-Malay-Muslim women as discussed above. This may be related to the ethnic differences in Malaysia regarding marriage choice and freedom as found by Chang and Jones:

> Chinese women have enjoyed more freedom to mix with males, from teenage years right up to marriage, than the other ethnic groups. Malay women had the least freedom to mix while Indian women were in an intermediate position [...] Most respondents had limited freedom of choice of marriage partner: they chose their own partner with parental approval, or they were consulted on the choice of a partner in an arranged marriage (Chang and Jones, 1990: 188).

Furthermore for Malay-Muslims, a 'runaway marriage couple is strongly condemned as these acts are seen to invite problems especially in hard times like incidence of marriage breakdown and other marital disputes' (Anis Shuhaiza and Noor 'Aza, 2010: 153). The need for many of the Malay-Muslim couples to conform to their parents' views was linked strongly to their religious beliefs. In Islam disobedience towards parents is strongly prohibited and filial piety is strongly encouraged. However Islam upholds the principle of the equality of all human beings (Ali, 2008) in which Islam does not prohibit marriage amongst those with impairment, yet those with mental disabilities should get consent from their guardian (Mohammed Ghaly, 2010).

As the research shows the Malay-Muslim women were restricted in marriage, not because of their religious doctrines, but due to the negative attitude of their family, or their prospective partner's family, who had greater control over them. The familial control and objection was evident in all three ethnic groups as discussed and not exclusive to Malay-Muslim women. Nonetheless because of their religious obligation that prevented them from disobeying their parents, many Malay-Muslim women were denied their right to marriage. It thus suggests that these women were also restricted from experiencing sexual intimacy and motherhood because in Islam sexual intercourse is not allowed before marriage. Also having a child outside marriage in Malaysia is taboo and against the social norms of the general population (Ng et al., 2006; Abdul Aziz, 2001). Therefore the societal negative attitudes towards disabled women, and the greater control of family over them, had profound impacts on these women's right to equal access to family life.

6.4 Meeting the challenges as 'disabled' wives and/or mothers

Many of the women interviewed continued to experience significant challenges even after they got married and/or became mothers. This final section will explore how these women faced major difficulties in terms of familial rejection, structural and attitudinal barriers and domestic violence and abuse that undermined their psycho-emotional wellbeing. However due to low number of participants with children, the discussion on motherhood experiences will only revolve around a few women.

6.4.1 Familial rejection

Although a number of women were able to get married despite familial objections, some of them were subjected to emotional and physical isolation. As the discussion in this section will show, these women were excluded by their families-in-law. For example Cornie Tan, who married a non-disabled man, described:

> Early in our marriage, my parents-in-law couldn't accept me. They openly showed their disapproval whenever I went to their house. When we had dinner together, they refused to talk to me and they even refused to look at me. I felt so upset and abandoned. I cried a lot but I told myself to be patient. My husband also convinced me to tolerate them because they were older. Then it took almost a year for them to accept me. It was not until I delivered my first baby. Only then they accepted me because I gave them a grandson

On the other hand Dilah was not rejected by her parents-in-law but was excluded by her husband's siblings from taking part in any family activities:

> My husband's siblings never communicated with me. They all have good careers and incomes. Sometimes they arranged family gatherings but they never invited us to go to their house. As a human being, I also have feelings. But they never cared. They treated us like outsiders. Even when they came to visit my mother-in-law who lives just next to our house, they never came to visit us. So I don't dare to talk or communicate with them. I know that we are poor and disabled that's why they never look at us.

Having married a disabled man Dilah was upset because she was not only abandoned by her own family (see Chapter 5, 5.3.1 and 5.3.2), but she was rejected by her family-in-law as well. She was thus not able to be a part of either family and this profoundly impacted on her wellbeing.

In a different situation Yasmin was ostracised by both of her families after she asked for a divorce from her abusive husband, who was also disabled:

> [...] both my own family and my in-law's family blamed me [after she asked for a divorce]. My ex-husband said bad things about me to them. He accused me of working day and night and forgetting about my duties as a wife. For almost 3 years my families isolated me and my children, they never came to visit us. When Eid [a Muslim festival after Ramadhan] came, my children and I stayed at home because we were unable to visit our family. Only after 3 years were they able to accept us after they knew the truth [that her husband abused her financially and abused her children physically].

Yasmin was thus blamed for her failure to fulfil her roles as a wife and the subsequent divorce. As discussed earlier, women in Malaysia are assigned to the primary roles of engaging with the family, marriage and children (Yun, 1984) and are primarily expected to focus on the family more than anything else (Chattopadhyay, 1997: 348; Noraini M. Noor, 1999). Therefore Yasmin was more 'disadvantaged' as a woman living in a patriarchal and traditional society. Her narratives will be discussed again in 6.4.3.

The strong denial of families-in-law towards women with impairment was found in Pushpa's narratives:

> I was a 'normal' person before this. I was working as a nurse, and then I was also a married person for the last 10 years. One day, I wanted to go back to my house to collect my clothes which were drying on the balcony. I fell from the balcony from the second floor to the ground floor, and I was also 5 months pregnant at that time [...] I broke my spine immediately [...] My husband took me to the hospital and the doctor told me that I'd be 'wheelchair bound' for life [...] This scared my husband and he asked 'what is going to happen to the family?' and we also had a daughter who at that time was 9 years old [...] With strong pressure from his family, he decided to divorce me at that time, right at the hospital.

This reiterates the findings on how family of non-disabled men could not accept disabled women as their family members. Such strong family influence and societal negative attitude towards women with impairment denied Pushpa's rights for family life just because she had an impairment. This undeniably damaged her self-esteem and left her with severe psychological wounds. Nevertheless she was able to 'bounce back' and regained her pride as a disabled woman (see Chapter 7, 7.4.2).

Despite the fact that these women continued to experience strong rejection from their families-in-law, some of them had to face rejection from their own children. Huifang for instance was upset with her 'failure' to become a good enough mother to her children. This was related in her daughter's attitude towards her impairment:

> My son never thought that I was 'handicapped' or felt ashamed of me but my daughter is ashamed of me. Previously I used to [come with her to] send her to school but then she wanted to walk with her friends to

> school. If I insisted on [coming with her to] sending her, she would ask me to stop my motorcycle [for disabled people] before reaching her school. She felt ashamed to be seen with me because I am 'handicapped'. I make my daughter ashamed of me (crying).

Huifang felt that her daughter embodied the negative attitude of Malaysian society towards her impairment. Consequently she felt distressed that she had 'failed' as a mother because her children did not want to listen to her and had problems at school:

> I went for medical check-ups to monitor my blood pressure every 4 months. I felt numb and trapped. I didn't know who I could share my problems with. Until a doctor asked me why my blood pressure was so high. I said that I couldn't sleep at night. He further asked if I was stressed out. Then I told him about my children. I was so stressed out with them. They refused to go to school, they made so much trouble. I even asked the doctor 'am I a failed mother? Am I really a failed mother?'

This had undermined her wellbeing as a disabled mother and led her to experience both physical fatigue and psychological distress. As a consequence these women experienced constant disapproval from their families, including their own children, towards them being wives and mothers with physical impairment.

6.4.2 Structural and attitudinal barriers

Huifang further described how she had struggled with constant barriers in taking care of her children because of her mobility impairment and lack of accessible infrastructures; as well as inadequate disability welfare in Malaysia.

> When I was pregnant, I had to queue like other people to see a doctor for regular medical check-ups. There was no 'special' treatment for disabled people like us. Although the treatment was free [for disabled people)], I had to wait a long time in order to see the doctor just like other patients. I was so uncomfortable because I cannot stand waiting for a long time.

In Malaysia it was not common practice to give priority to disabled people in public places, including hospitals. However in recent years the government started encouraging its agencies to prioritise disabled people and the elderly in public affairs - especially in healthcare settings as underlined in the PWDA 2008.

Huifang also added that she encountered significant structural barriers during her pregnancy:

> I was stressed after I became pregnant - I could not stay on an upper floor because I had to use a wheelchair instead of crutches. So I moved to a ground floor flat. Then, we had financial problems because I couldn't work at that time due to my pregnancy and we had to pay extra for the ground floor flat.

Due to inadequate disability welfare in the country, appropriate support for disabled mothers was not given. There was no specific aid to support disabled people with accessible housing. As a result of her decreased physical abilities during her pregnancy Huifang encountered structural barriers in her home setting and subsequently faced financial barriers in relation to that.

Moreover after she had her baby she continued to meet challenges due to a lack of transportation and the inadequate support system:

> For a few months after delivery, my baby always fell sick. He always got stomach pains. So I had to bring him to the [private] clinic every time he fell sick late at night. It was really difficult at that moment. We didn't have a car, so we asked our friend to help us. Then sometimes when we arrived at the clinic I had to call the nurse to carry my baby inside because I could not carry him with crutches. The clinic was not accessible for wheelchairs so I had to use crutches. Because we always asked our friend to bring us to the clinic he got angry with us. He said that we always bothered him, why don't we call other friends but we had no choice. It was not easy. It was so stressful at that time.

Although Huifang and her husband were registered as disabled persons with the DSW, they were not given any financial or disability support. As such they could not afford to have a car and had to depend on their friend. Such dependency on a non-family member, structural barriers in healthcare settings and inadequate support from the welfare state had systematically exposed them to negative outcomes that caused them to experience mental distress for being disabled parents.

Likewise Eryna, who used a wheelchair, had to overcome her physical limitations in order to look after her baby alone; without adequate support from her family and the welfare state:

> I was hospitalised for almost 2 months because of complications before I delivered my baby -. My son was delivered prematurely and he had to spend a few weeks in ICU. I nearly lost my son when he stopped breathing several times. I could not describe my feelings at that time because I was all alone as my husband wasn't there […] During the confinement period, I looked after myself because my husband had to stay in the hostel for [sports] training and no one was at home to help me. I still remember one time my baby stopped breathing again at home and I rushed to the hospital all by myself. Thank God that the doctor was able to save him […] I really love my son as he is everything in my life and I can't afford to lose him.

Despite the lack of support from the welfare state and her family Eryna managed to look after herself and her baby because she had a car and lived in a city, improving her access to the hospital. Yet this had a profound impact on her wellbeing as a disabled mother and led her to experience both physical and psychological fatigue.

Another important facet of the disabling experiences of disabled mothers was having to face the societal negative attitudes towards their ability to become mothers. Huifang again disclosed:

> I worked for like a year then when my children had a lot of troubles at school and outside school, then I quit. I quit helping my husband at his shop. He had to find someone else to help run the business. So I focused on looking after my children. Every day I went to their school to bring meals for them. Until one day, I waited for my children outside the school. An aunty who was also waiting for her children asked me 'why should you have children? Why do you want to have kids?' I was uneasy at that time. She asked very painful questions. So I said to her 'why can't I have children, aunty?' Then she replied 'you are like this [referring to her disability] and you still want to look after children? Don't you think it is difficult?' I was so upset with her words. But when I considered the fact that she was an older woman, I didn't reply further. I didn't want to answer again and I just smiled at her but in my heart I was so deeply hurt. I was upset about why people could think like that towards us. Then she further said 'Don't you have someone else at home that can help you send the meals to your children?' I replied, 'if I had someone to help me then I wouldn't have to come'.

The broader literature indicates that disabled women often struggle to have their right to bear children recognised (Finger 1990; Lonsdale, 1990; Thomas, 1997; Kallianes and Rubenfeld, 1997; Smith et al., 2004). This directly links to the dominant notion of how women are always perceived within society, as Malacrida argues:

> Women are expected to aspire to norms of femininity that include ideal motherhood, where mothers are positioned as ever available, ever nurturing providers of active, involved and expert mothering – indeed, being a caregiver is a master status for adult women in modernity. While this may be the case for all women, mothers who are disabled can have more a complicated relationship to ideal motherhood than others, because they are perceived of either as asexual and inappropriate to the role of motherhood, or conversely because they are seen as sexually victimized and at risk (Malacrida, 2009:99).

Thus women with impairment were exposed to societal pressures to prove that they could be 'good enough mothers' (Thomas, 1997: 622) and this certainly posed significant burdens to these women; physically and psycho-emotionally.

6.4.3 Domestic violence and abuse

In section 6.2.3 it was examined how some of the women were exposed to financial exploitation by their partner and that that significantly correlated with their gender and disability. These women continued to experience such power domination by men when they got married and often they were also subjected to domestic violence and abuse as this section will verify.

Yasmin, as discussed in 6.4.1, detailed how her ex-husband abused her financially and beat their children:

> I worked so hard to support my family because my husband didn't want to work. I still remember that I used to run a food stall in the area of my flat. It was OK and I could rent a flat and buy a motorcycle. Financially we were stable at that time. We just had 3 kids at that moment. But my husband never wanted to help. He mixed with gamblers and was involved in gambling activities. He took all the money that I earned from my business. But I never told anyone; including our families. Then we moved to X and I worked in a factory. Every day I used to wheel my wheelchair to the workplace for almost 2 kilometres. I worked so hard; more than anyone else […] Sometimes I gave my children school money but he took it from them. He brought my children to the lottery shop

> and taught them that playing the lottery could help them become rich. Oh Allah (God), I worked so hard day and night to earn living and he took it to buy lottery tickets? […] Then I decided to ask for a divorce because he beat my children. I spent a lot of time at the workplace so there was no one at home and I was worried for their safety. I was so upset when he threw a hoe at my youngest son. Fortunately it didn't hit him if it had he would have died. That was the trigger point that made me determined to ask for a divorce.

Likewise Eryna, who was also married to a disabled man, experienced mental distress due to the constant financial trouble created by her husband:

> For me, from the start I regretted getting married because I never felt happy with him. He always creates troubles for me because he has many debts and he cheated me many times. When people can't find him, they look for me. I felt stressed and embarrassed because my husband took their money. I used my savings to pay his debts. The only thing that makes me not feel regret over marrying him is my son. Because of my baby I can tolerate all the things he has done to me.

Clearly Eryna hesitantly accepted such financial exploitation and remained in her marriage solely because of her child. These women were not only subjected to financial abuse by their husbands but also physical violence and psychological torture as uncovered by Huda:

> I felt stressed. It was a prolonged stress. He did not want to answer me when I spoke to him. He has become fiercer now. I cannot open my mouth even to ask about something. One time, he became violent towards me […] He lost control and slapped me. That is why I have kept silent until now. I cannot say anything. When I say something, he will get angry and beat me. So I just keep silent although I have many things to say in my mind.

Likewise, despite these occurrences, Huda still decided to continue with her marriage for the sake of her children. Whereas Dilah disclosed that she was subjected to sexual, psycho-emotional and financial abuse by her disabled husband instead of physical violence:

> **Me** : How do you feel about your marriage? Are you happy?
>
> **Dilah** : It's too late to regret. I never feel happy with him. Never!

Me : Never?

Dilah : Yes, never. Although he never physically abuses me, but he never talks to me. He is fine with his friends but with me at home, he never wants to talk to me or have fun with me. We only talk about important things. We never laugh together. I don’t know how to laugh with him. We just do our own business.

Me : What about your sexual life with him?

Dilah : He couldn’t give me anything. He can’t in terms of sexual ability. I have asked him to divorce me but he didn’t want to let me go. He said he will never divorce me - ever. So, I have to accept it although it’s hard. For me, my life now is just to live day by day until I die. We live like strangers under the same roof but we have never felt happy

She further added:

Dilah : I am the one who pay for all household expenses

Me : He is not working?

Dilah : No, he just stays at home. Although I have been married to him for many years [over 20 years], I still don’t understand him. I don’t know if he is lazy or what. I really don’t know

In this case, Dilah was more ‘disadvantaged’ because she had lack of agency as a result of her impairment which subjected her to attitudinal barriers in education (see 4.2.2) and familial abandonment (see 5.3.1). As a woman with a poor education, Dilah lacked knowledge of her right to file a divorce against her husband and her restricted social activities did not allow her to seek advice or help from others. Moreover she had no family or close friends to fall back on with the absence of her husband and thus she had little opportunity to seek liberation from such an abusive marriage. Consequently she reluctantly stayed in her marriage despite her physical and psychological needs being endangered.

Hence the incidences of domestic violence and abuse experienced by these women have strong correlation with the broader trends in Malaysia. Women in general are exposed to higher risks of violence at home from partners and family members: this based on the high degree of reported cases (Rashidah et al., 1995; Ministry of Women, Family and Community Development, 2004). Also many women did not report their case and seek help often because they were afraid of the abusers or circumscribed by the social stigma of being divorced and the resulting impact on their children. It therefore suggests that women with impairment are more ‘vulnerable’ to such domestic violence and abuse because they felt ‘powerless’ as a result of both their gender and disability.

6.5 Conclusion

This chapter has discovered how the women with impairment experienced love, marriage and motherhood in Malaysia. It examined how their experiences of disability were not simply from the result of societal oppressive attitudes towards them that restricted their opportunities for equal access to family life. Instead more complex scenarios emerged between the individual constraints, familial control, and sociocultural influences. These intrinsic aspects and contextual factors of living in a patriarchal and traditional society significantly undermined the wellbeing of the disabled women.

Nevertheless many of those interviewed refused to give up their hope of having a family life despite the constant struggles they encountered in their pursuit of happiness. Many of these women felt lonely as they grew older and they wished to have partners. Most importantly, many of them wanted to get married and have their own children as this is highly valued in Malaysian society. However their aspirations to experience life, like other Malaysian women with a husband and children, were restricted and this caused them to experience significant psycho-emotional disablism. While some of them were able to fulfil their right to form a family, often they encountered significant barriers in negotiating their identities and meeting their needs as disabled wives, daughter in laws and disabled mothers. They were constantly reminded that they were ‘disabled’ and not worthy of experiencing life like other women. All these challenges emerged from strong familial objections, structural barriers at home, healthcare settings, and stigmatisation in public places, in addition to negative societal attitudes in relation to their abilities to become wives and mothers.

Thus the next chapter will bring together all key challenges they faced in constructing their narratives as women with impairment.

Chapter 7: Identity Constructions

7.1 Introduction

The analysis presented in the previous three data chapters uncovered the central core of the lived experiences of 33 Malaysian women with mobility impairments. In Chapter 4 we learnt how poverty, geography and impairment played a vicious circle of disablement experiences that intersected with structural and attitudinal barriers. In Chapter 5 the dynamics of familial interactions were explored in terms of support, conflict and gender roles within the family that undermined the wellbeing of the women interviewed. In Chapter 6 the discussion focused these women's rights to form (personal) relationships and to have a family life and how they were constantly challenged. This final analysis chapter brings together the key challenges experienced by these women in constructing their identity. Through their narrative accounts, the data suggests that the participants were subjected to significant social forces in constructing their self-identity. As Jenkins argues, drawing on the ideas of Goffman:

> Individual identity – embodied in selfhood – is not meaningful in isolation from the social world of other people. Individuals are unique and variable, but selfhood is thoroughly socially constructed: in the processes of social interaction within which individuals define and redefine themselves and others throughout their lives (Jenkins, 1996: 20).

As this chapter will show, it was through social interactions with others that the women formed, reformed, and negotiated their self-identities. As discussed in the previous data chapters, the participants were subjected to the structural and cultural barriers in many aspects of their lives that served to undermine their sense of self. Somers proposes that:

> A narrative identity approach assumes that social action can only be intelligible if we recognise that people are guided to act by the structural and cultural relationships in which they are embedded and by the stories through which they constitute their identities (Somers, 1994: 625).

Whilst the social interactions significantly influenced how women identified themselves, their identity construction was often more complex and reflexive: it was dynamic and varied in different contexts; as Giddens (1991: 53) has written, ‘Self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of his or her biography’. Therefore this chapter will show how the participants identified (or not) as ‘disabled’ in many different ways and how this was related to their social interactions with others, impairments, gender, cultural and religious norms.

7.2 Reinforcing the ‘disabled identity’

Chapter 5 presented examples of how many of the women interviewed were significantly influenced by their family in many aspects of their lives. The inadequacy of state’s welfare system worked to reinforce the strong reliance on family as the primary support system. These women were strongly conscious of how their presence and impairment affected their relationships with family, friends, and people surrounding them because they had few opportunities to be independent. Also, as observed in Chapter 4, many women were psycho-emotionally affected by the negative attitudes exhibited towards them by their friends, teachers, employers and significant others. They valued how other people perceived them and this significantly impacted on how they viewed themselves. The data revealed that of the 33 participants, the majority of them identified themselves as ‘disabled’ and this strongly linked to their social interactions with others. It was observed that they were heavily affected by the cultural representations of ‘disability’ and ‘femininity’ in Malaysian society, and the absence of disabled people in public spheres. This section therefore will discuss how these social aspects reinforced the formation of ‘disabled identity’ among the majority of women.

7.2.1 The cultural representation of ‘disabled people’

In the previous analysis chapters many informants talked about how, for most of the time, they were ‘rejected’, ‘devalued’ and ‘differentiated’ by other people because of their impairment. They experienced constant ‘disapproval’ from people surrounding them in home, school, workplace, public spheres and personal life. They were constantly reminded that they were ‘different’ and ‘worthless’ by their families, friends, colleagues, teachers, employers, partners, prospective families in law, and even strangers. Through such daily encounters with others in their private and public lives, many women felt ‘discredited’ as individuals and thus it reinforced the cultural representation of ‘disabled people’ as a ‘spoiled identity’ (Goffman, 1968). Consequently many women tended to focus on the negative aspects of being disabled and acquiesced to the cultural stereotype of what being disabled is. This significantly influenced how these women identified themselves as ‘disabled’.

In discussing these findings *Stigma*, the work of Erving Goffman (1968) which examines the experience of ‘spoiled identity’, becomes central to the analysis. In *Stigma,* it is society which ‘establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories’ (Goffman, 1968: 11). Goffman argues that one’s appearance enables us to place him or her into a category and grants a specific attribute that is his or her ‘social identity’ (1968: 12). The concept of ‘normality’ is also assumed and one who is ‘different’ from the category allocated to him or her will be ‘stigmatized’ and reduced ‘from a whole and usual person to a tainted, discounted one’ (Goffman, 1968: 12). For example people with a stigma, like those with a visible impairment, are assumed to be not ‘quite human’ and face discrimination which reduces their life opportunities (Goffman, 1968: 15). Also Goffman talks about people who are stigmatized themselves adopting the stigma and agreeing with it (Goffman, 1968). Thus, stigmatized persons who display an unacceptable difference in their social interactions (between the ‘normal’ and the ‘abnormal’) are constantly striving to adjust their social identities.

As observed in this study (see Chapter 5), many of the women had to meet the challenge of fitting in to the structure of their own family as Yana said:

> I feel upset as my parents treated me differently. Yes, I know that I am disabled - that’s why they treat my brothers and sisters better than me.

Yana felt that she was ‘disabled’ not because of anything internal to her (e.g. her impairment) but because her parents treated her differently and this made her aware of her disability. As a result of such different treatment in her family, she developed low self-esteem and felt inferior to her siblings. This was also experienced by Imah who perceived herself as ‘disabled’ because of her siblings’ negative attitude towards her:

> Yes, I know that I am disabled that’s why they [her siblings] look down on me.

Likewise Yasmin was also upset with the attitude of her family towards her:

> It was not your neighbour or someone else but it was your own family members who looked down on you. You don’t need people telling you that you are such a ‘pitiable’ person. Don’t use those words. It will only let me down.

This negative treatment experienced by these women made them feel ‘discredited’ as a person. This challenged their identity formation and hindered them from being a ‘credited’ member in their family. Yana for instance always felt that she had no value in her family because of ‘constant disapproval’ from her parents, as discussed earlier. This significantly impacted on her self-esteem not only within her familial environment but it also extended to her friendships. She avoided making good friends with other residents in her sheltered employment:

> I don’t have close friends here, not even one. I can’t be close with them because I feel difficult to trust them. I don’t know, maybe I am used to being alone [...]

The ‘disapproval’ treatment that she received in her family heightened her ‘distance’ from her colleagues and thus it prevented her from developing a close friendship with anyone. This can be directly linked with Thomas’ notion of psycho-emotional disablism (2007; Reeve, 2012) working within her familial interactions. In this respect Dilah, who was ‘rejected’ by her father and her step siblings after she had her leg amputated (see 5.3.1 and 5.3.2), also experienced psycho-emotional disablism in which she gave up her hope in developing friendships:

> But for me I can’t. I have an intense level of low self-esteem although I have tried to overcome it in many ways. That’s why I said that I don’t have many friends. I am afraid to get close to other people because I

> don’t want to hurt them. That’s why it’s hard to have friends, if I do have some friends, I am afraid that I will say something they don’t like. So for me it’s better to not have close friends […] I don’t have close friends who I can laugh and cry together with […]

As discussed in the previous analysis chapters, family played key roles in the lives of the majority of the women and as such it influenced their identity formation. The effect of psycho-emotional disablism (Thomas, 2007; Reeve, 2008; 2012) within familial interactions could be extended to other interpersonal relationships as experienced by Yana and Dilah. This ‘spoiled’ their sense of self and prevented them from having a positive social identity. Such disablism not only affected their identity formation, but it also led them to social isolation because ‘friendship is important for emotional, practical and even medical reasons’ (Shakespeare, 2006: 169). Therefore the negative interactions that took place between these women and their family members reinforced the idea that ‘disabled people’ in Malaysia were ‘different’, ‘spoiled’ and ‘worthless’ and this encouraged them to develop low self-esteem.

The notion of ‘disabled people’ being identified as ‘different’ and ‘spoiled’ was not only reinforced at home but also at school; as described by Wei Yin:

> My Science teacher said to me when I was in form one [14 years old], ‘now you are a teenager, why don’t you register as a disabled person?’ […] I felt angry and looked straight into her eyes. I said ‘what is my difference? I am ‘normal’. I can play, ride a bicycle, swim and climb hills. It is just that I can’t do it fast - that is my only weakness. So, am I different?’

For many women ‘difference’ came from others and not from themselves, as described by Wei Yin. Their ‘difference’ was seen as a ‘spoiled identity’ not only within the familial environment but also within an educational environment. This significantly undermined their psycho-emotional wellbeing and affected their identity formation as described by Alice Chong:

> When I was small, I used crutches most of the time. So my friends looked at me differently. I felt depressed at that time [...]. There was one time the kids in my school called me ‘handicapped’, you know. A few girls suddenly came to me and called me ‘handicapped’ and scolded me. I could not take it, you know (cracking voice). So I cried and went back home and blew all my anger at my mum. I was crying - I thought my mother wanted to let me die. I thought she sent me to school so that children could make fun of me. I didn’t want to go to school for a week. I was so hurt [...]

The cultural representation of disabled people as a ‘spoiled identity’ was not only exhibited within familial and educational interactions, it was also apparent in the workplace. Shakespeare (1994: 288) argues that disabled people ‘are viewed as passive and incapable people, objects of pity and of aid’. They are perceived to be someone in need of help (Brickman et al., 1982; Jones et al., 1984; Katz, 1981). This was reiterated by the previous approach of the Malaysian government in handling the issue of support for disabled people, as they focused on the concept of a welfare-based or ‘caring society’ (Kuno, 2007:99). The efforts to foster social participation and independence of disabled people in Malaysia are strongly linked to the charity context rather than within the equality or human right context (Kuno, 2007). Therefore, women with a visible impairment were perceived as having lack of autonomy in performing their work and always needing help. As Huifang said:

> I was so stressed when I worked there. Whenever I made a move - even a little bit, my friends [other workers] would ask ‘Are you OK?’, ‘Can you do it?’, ‘Do you need help?’ I felt like a sick person!

The ‘over-protective’ attitudes displayed by Huifang’s colleagues made her feel like a patient in the hospital. This significantly undermined her ability to exercise her agency as an ‘able’ worker. This feeling was also shared by Nora:

> One more thing, for me who uses crutches, some people [in her workplace] tend to show their pity towards me. They like to help me. I always say ‘it’s fine, I can do it’ because I like to be independent. I don’t like people pampering me. I have a disease where I can’t let myself be inactive otherwise the virus will become rapidly active. That’s why I don’t like that people always want to help me. I like to do it by myself. If I can’t do it, then I will ask for help

The informants were not only viewed as ‘different’, ‘spoiled’ and ‘worthless’ at home and school, but their capability to exercise their agency in employment was also questioned. Furthermore as discussed in Chapter 1, the primary role of women in Malaysia is perceived as that of home-maker (Koshal et al, 1998; Noraini, 1999; NGO Shadow Report Group, 2005; Aminah, 1998; Chattopadhyay, 1997:348) and women are always portrayed as ‘weak’, or dependent on male characters, and should always be protected (Azman and Juliana, 2005; Rohana, 1997; Wang, 1994 and 2000 cited in Azman, 2006). Faridah (2003) also found that disabled women in Malaysia faced significant discrimination in their career experiences in terms of job appointments, career appraisals, physical barriers at the workplace and work related places, lack of support from leaders and lack of understanding about disability issues exhibited by employers. Therefore Huifang and Nora might not only be viewed as ‘weak’, ‘dependent’ and ‘pitiful’ because they were disabled, but also because they were women. Such cultural representation of ‘disabled people’ and women in Malaysia prohibited them from becoming active social agents both in their family and in society.

Chapter 4 presented many examples of how women were systematically excluded from wider economic and social participation in mainstream society. Due to their invisibility in public places, many people are not aware of disabled people and have very little contact with them. They do not know how to react around them or how to speak to disabled people. All of the women talked about how they often became the centre of unwanted attention and many of the women interviewed told how they had experienced psycho-emotional distress whenever their presence in public captured other people’s attention, attracting the public’s gaze. This had negative impact on their identity as ‘disabled persons’ and influenced their identity formation.

For example Alice Chong felt that she was like an ‘alien’ in public places:

> Previously I felt very low - I cried a lot because I am ‘handicapped’. There was one time when I was walking in a supermarket, a guy who I didn’t know looked at me from head to toe. He stared at me as if I was an alien. It made me feel irritated. Our society cannot accept, as you know. After that I cried for many days, you know. I felt myself to be like an alien. It made me feel very small and hurt. I didn’t want to be ‘handicapped’. So what am I going to do? I also want to be ‘normal’

Similarly Jiaying was frustrated over public reactions towards her visible impairment:

> Well, until now when I went out with my siblings, there were many people - no matter whether it was children or adults, who stared at me. How to say? We felt that they stared at us but didn’t know if it was sincere, mocking or disgusted.

The above scenarios disclose how the scrutiny of members of the public undermined the psycho-emotional wellbeing of these women as stares and individual examination leave disabled people feeling excluded, worthless, unattractive and stressed (Thomas, 1999). By being exposed to the gaze of strangers (non-disabled) in public, these women felt invalidated (Reeve, 2008; Loja et al., 2013), invoking psycho-emotional disablism (Thomas, 2007; Reeve, 2008; 2012). This made them felt upset and pressured when making an appearance in public. As Nora described:

> I felt so upset because I couldn't go out and even if I went out, I had to use crutches. People looked strangely at me because I used crutches. I felt isolated like I am...you know that I easily get stressed out because of my health condition. When I saw people looking at me, I felt angry, I felt like asking them why they looked at me? Did they never see people? I felt like saying that to them. Sometimes, I kept myself hungry rather than going out to buy food. I felt so ashamed. It was OK if they looked at me once but they kept looking at me again and again. Then they *pot pet pot pet* [mumbling] talked to their friends. So I felt so ashamed and then after that I never went out to buy food.

Nora's experience can be linked directly with Thomas' notion of 'barriers to doing' (Thomas, 1999: 47). Through this process of social exclusion Nora was prevented from achieving what she desired and it left her feeling 'vulnerable' in public places. Nevertheless, for some women, prolonged exposures to unwanted staring have led to them becoming 'immune' to such public reaction as Prema said:

> People like to stare at me like I want to beg for money or what. But I ignore them because I used to that. Sometimes, when I wanted to pay the electricity bills, internet [bills] etc, I went to the TNB [Tenaga Nasional Berhad] and people used to stare at me. But I didn't care I just ignored them.

Watson (2003) argues that daily denials of disabled people's existence in public invoke a routinisation of oppression towards them. They became inured to such daily oppressive experiences and some of them managed to develop coping strategies in their daily encounters to overcome such oppression (Reeve, 2012) as described by Zahra:

> People like to stare at me because they see me in a wheelchair, right? Maybe they think 'why is this girl in a wheelchair?' But now I don't

> mind. I even climbed the cinema staircase (laughed). What is important is that I am also like other people, like them. It's just that my physical ability is limited compared to others - that's the only difference. Before this, I felt afraid, shy and embarrassed. I thought if only they could accept me? Well you know people stare at me like I am very strange. But now I no longer care. I even give them a big smile if they smile at me.

In this respect Zahra's pragmatic approach in returning the public gaze with a big smile and 'doing' what was seen by non-disabled as 'abnormal' helped to overcome her anxiety towards public staring. By doing this Zahra behaved in the opposite way (to her genuine feeling of being upset) to defend herself from further psycho-emotional harm: she employed 'reaction formation' as a defence mechanism (Freud, 1937). A person who adopts this type of defence mechanism will go beyond denial and behaves in the opposite way to what he or she thinks or feels (Freud, 1937; McLeod, 2009).

This section has presented strong evidence of how many of the women interviewed were viewed as 'different', 'abnormal', 'weak', 'dependent' and 'pitiful' through their social encounters with others. Such negative attitudes towards these women constantly reminded them that they were 'disabled', causing them to experience psycho-emotional disablism and thus restricting their full potential (barriers to being) and preventing their full participation in society (barriers to doing).

7.2.2 The absence of public role models

In the above section it was discussed how the wider social and economic exclusion towards disabled women influenced how they were viewed in society and how this affected their identity formation. This can be directly linked to two main consequences: 1) their limited presence in public places meant that many people (non-disabled) had very little contact with them and thus led to unwanted attention or stares, stigmatisation and prejudice towards disabled women, 2) poor representation of disabled role models in the public domain disempowered disabled women: this latter factor will become key element discussed in this section.

Being disabled in Malaysia is complicated by the fact that there are very few positive public role models. Not only are disabled people rarely seen on the street, they are also almost entirely absent from the media, television, or other forms of public life. As discussed in the previous analysis chapters, many women were systematically excluded from full participation in society. They spent much of their time within their home environment because many of them lived in remote areas and poverty. The family played a key role for them and they had very limited contact with the wider population (both disabled and non-disabled people) so their recognition was almost totally absent in public. Therefore many of the women only came into contact with other disabled people when they left home to obtain vocational training at disabled people's institutions or when they became disabled. It was only later in these situations that they often developed positive attitudes towards their impairment and this significantly influenced their identity formation.

Intan, who was born with an impairment, related how she gained her confidence after her first interaction with other disabled people and her subsequent identification of herself with a 'disabled identity':

> I came from a village and never came across any disabled people. I thought everyone was fine except me. Then, when I studied at the institute I saw many disabled people with more severe impairments than me. Oh Allah [God], they were in a worse condition than me. I thought I was the only one. Since then, I have felt proud of myself.

Moreover Lijuan, who was born with an impairment, felt empowered by knowing other disabled people, and was then inspired to lead an independent life:

> I felt happy when I studied there [at a disabled people's institution]. I met with many disabled friends. I saw many of them went out, even those with more severe impairments than mine. So, I thought if they can have an independent lifestyle, I also can be independent [...] Previously, I never thought that I could be independent, I just stayed at home most of the time.

Their interaction with disabled role models gave them positive perceptions of a disability identity and it eventually increased their self-esteem. In the previous section it was observed how many women were perceived as 'different', 'spoiled', 'weak' and 'dependent' by people surrounding them and this caused them to develop low self-esteem. The significant exposure to other disabled people, as described above by Intan and Lijuan, changed their perceptions towards themselves. The positive social interactions that took place between these women and their disabled peers gave them new insights into their ability to lead an independent life and empowered their sense of self as 'disabled persons'. Although the segregated educational or training for disabled people excluded them from mainstream society, this was the only means for them to come into contact with other disabled people. Therefore it is important to have positive representation of disabled role models in Malaysian public spheres, especially for those who were born with impairment.

Women who acquired impairment later in their life were also affected by the absence of disabled role models in Malaysian society. Yasmin who acquired impairment at age 16 described:

> After the accident, I locked myself up for 2 years in my room. I never went out except for medical and traditional treatments. I didn't want to meet anyone at all. One night, I heard about an institute for disabled people on the radio. I applied and I was accepted. It was my first time living outside my room after two years since the accident. I observed there were many others with more severe impairments than mine. I learned from them that my life is not practically over. Since then, I told myself that I wanted to be independent just like them.

The lack of exposure to positive disabled role models has made Yasmin much more susceptible to psycho-emotional disablism. Drawing on Bury's concept of 'biographical disruption', the onset of chronic illness (in the above case it refers to impairment) has a disturbing impact on self-perception and identity 'exposing the individual to threats to self-identity and the potentially damaging loss of control' (Bury, 1997: 124). As Yasmin acquired her impairment in her adolescence this crucial transition period challenged her identity formation from young 'non-disabled' to young 'disabled' person, and this biographical disruption brought unexpected pain and suffering to her. Living in a society that has very low representation of positive disabled role models in the public and media, and also a persistent negative cultural representation of disabled people, Yasmin had little confidence to carry on her live with disability. However her initial interactions with other disabled people after the onset of her impairment informed her that living with impairment was not something 'too bad'. Such positive social interactions with disabled peers helped her to change her negative perception towards disability identity as a ‘spoiled identity’ to a positive one. This is an important aspect of identity formation for many women because the majority of women interviewed (21 out of 33) were not born with impairment but acquired it through many different ways.

Likewise Deepa, who acquired her impairment in a road accident at age 21, also described:

> When all the visitors [at the hospital] came and went, at night it was just me and my disability. So I was, I didn’t go into a deep depression but I was aware of you know, the things I had lost and that I wouldn’t be able to walk […] So it was like not until two ladies you know who are in a wheelchair […] And these two ladies came to visit me on two separate occasions […] And they were confident, and when they came to speak to me, that was a turning point for me. I thought to myself if they can continue life in a wheelchair you know, I should be able to […]

The above examples demonstrate that the absence of disabled roles models in Malaysian society not only affected how ‘disabled people’ were perceived and identified but it also impacted upon identity formation of the women with impairment. For these women the effect was even greater when there was no possibility for self-affirmation. The self-affirmation theory asserts that:

> People have a fundamental motivation to maintain self-integrity, a perception of themselves as good, virtuous, and able to predict and control important outcomes. In virtually all cultures and historical periods, there are socially shared conceptions of what it means to be a person of self-integrity. Having self-integrity means that one perceives oneself as living up to a culturally specified conception of goodness, virtue, and agency (Baumeister and Vobs, 2007: 787).

Therefore the negative cultural conception of ‘disabled people’, and the absence of positive disabled role models in Malaysian society, reinforced the idea that people with impairment have a ‘lack of self-integrity’ and ‘lack of agency’. By coming into contact with other disabled persons many women with both congenital and acquired impairments recognised that their identity as a disabled person was not something unusual - as ‘knowing that you are not alone with problems that you may have believed were unique to you’ (Wendell, 1996:12) was very important to them. They eventually developed an understanding of their own experiences in relation to other disabled persons' experiences that advanced their feeling of self-worth (Crow, 1996). Consequently such exposure to positive disabled role models empowered them to have self-affirmation as 'disabled persons' and helped them to form, reform and negotiate their identities.

7.2.3 'Being feminine' and/or 'being disabled'?

The women interviewed were not only constantly challenged to negotiate their identity as 'disabled persons' in Malaysia's disabling society, but they were also challenged to establish their gender identity. Morris (1991) argues that being disabled is a gendered experience and women's narrative identities were acquired through their reference to gender norms that made up their social worlds (Thomas, 1999; 2001). As discussed in Chapter 1, Malaysian society reinforced strong traditional gender roles and stereotypes of how women should look and behave. Those who do not conform to such gender roles and stereotypes are against the cultural norms. In Chapter 5 it was discussed how women had difficulty in negotiating their gender roles within the familial environment because of their impairment. This section will discuss how women were challenged to incorporate their gender identity or femininity into their identity formation.

Gender identity refers to the degree to which one sees herself or himself as feminine or masculine in a given society (Burke et al.1988; Spence, 1985). The socially-constructed feminine role that asserts the beauty and efficacy of the female body (Butler and Bowlby, 1997) has been established and maintained within society (Begum, 1992). For women with visible impairment these established norms pose a 'threat' to them being seen as 'beautiful' and 'attractive' because they feel that their impaired bodies could not conform to the societal template. As Huifang described:

> They [her sisters] dressed beautifully and put on make-up like real women. But me? I felt so isolated and different. As a woman, I also want to become beautiful too like them, but I can't. Then I realised that I am a disabled woman - that's why I am different.

It was interesting to observe that Huifang was not feeling ‘different’ because she had an impairment, but because she was unable to fulfil her gender identity of ‘being feminine’. Again it was through social interactions with others, and in this case through familial interactions, that Huifang felt that she was ‘different’ because she did not regard herself as ‘being beautiful’ like her sisters. This cultural conception associating ‘being a woman’ with ‘being beautiful’ intersected with Huifang’s impairment, reinforcing the idea that an impaired woman could not be accepted as ‘being feminine’ because their body was ‘different’ and ‘impaired’.

Likewise, Azni felt upset because she was incapable of emulating her friends by dressing beautifully and wearing high heeled shoes:

> I was fine with most of my friends as they were nice to me. However, sometimes I felt a little bit different, especially in terms of dressing. I saw them beautifully dressed and putting on high heeled shoes. But I can’t wear high heeled shoes, so I felt quite upset with myself […] I also want to become beautiful too.

Here the social construction of ‘difference’ was not only reinforced through the cultural conception of disability but also femininity. These women had adopted the cultural values of physical attractiveness and embodied femininity. They found that their physical appearance did not fulfil typical expectations, which caused them to suffer a distorted self-image due to their physical appearance differing from societal norms (Lonsdale, 1990). This can be linked directly with Thomas’ notion of ‘impairment effects’ (Thomas, 1999) that observed that these women felt restricted to ‘being feminine’ because of their impairment and, as a result, they felt more ‘disadvantaged’ as a woman than as disabled.

Whilst Huifang and Azni felt ‘disadvantaged’ because of their impaired body ‘failed’ to conform to the notions of femininity, Murni was prevented from embracing such feminine attributes:

> Since I was young, my mum never dressed me like a girl. She always put on pants [trousers] and t-shirts on me. She said that I have to be tough like a boy. She did not want me to become gentle and weak like girls. She was afraid that I would be bullied by other kids because of my impairment. In her mind, it was better to dress me like a boy so people would see that I was tough and would not bully me. Because of

> that, I never liked being like a typical girl or a woman. It's not 'me' to be like a gentle woman and so on.

Murni could not be 'feminine' because her mother associated it with being 'weak' and 'vulnerable' and this linked directly with how disability and femininity are perceived within Malaysian society. By having an impairment, Murni's mother thought that she would not only be disadvantaged as a girl, but even more as disabled, and thus the societal oppression and discrimination towards her daughter would be 'multiple'. This reinforced a dominant construct that Malaysian women are always second to the men (Noraini, 1999) and are always perceived as 'weak' (Azman and Juliana, 2005; Rohana, 1997). As discussed earlier family played a key role in the women's lives and Murni was no exception to this. As a result she was prevented from articulating her gender identity as she wanted:

> You know that there were times when you realised that you were not attractive like 'normal' people. Like you know that you don't have a boyfriend because you don't wear feminine clothes. You know that I always wear boys' clothes so I don't look attractive to men. These kinds of things make you aware of your disability.

She not only had barriers to 'being feminine' because of her familial influence and her impairment, but she also had barriers preventing her from forming romantic relationships with men because she was not 'feminine'. Whilst incorporating femininity into her identity was perceived to multiply the discrimination and oppression towards her, embodying masculinity would also disadvantage her romantically. This intersection between family's control, gender and impairment made Murni aware of her disability and it created a constant dilemma for her in negotiating her disability and gender identities. Therefore she felt disadvantaged by being both a woman and disabled.

It was important to observe that these women felt that they could not accomplish 'being feminine' and 'being disabled' at the same time. As women with visible impairment, their identities as 'disabled' and/or 'women' were seen as 'spoiled identities'. By being 'disabled' they felt that they could not conform to the feminine attributes and even if they conformed to the feminine attributes they felt that they might be subjected to the societal oppressive attitudes towards disabled people and women in Malaysia.

7.3 (Dis)crediting a disabled identity

The previous section discussed how the Malaysian society reinforced the cultural conception of disability as a ‘spoiled identity’. Many women were identified as ‘disabled’ by people surrounding them at home, school, in the workplace and in public places that undermined their self-worth. Through such daily encounters many women internalised the oppressive attitudes towards them and identified themselves as ‘disabled’ and ‘different’. Nevertheless not all women subscribed to the societal conception of a disabled identity. Some of them refused to be branded in this manner. However this notion of identification with (or without) disability was dynamic and reflexive. It changed over time and varied in different contexts and situations as the following will reveal.

7.3.1 Rejecting a disabled identity

Murni, who acquired impairment when she was 3 years old, was informed by her mother from a young age that she was not disabled:

> When I was small, I went for traditional massages. We also went to shamans but I don’t really remember, I was small at that time and I don’t believe in those things. Then I see that our people, Malay actually, they like to go for traditional treatment over and over again. They believe that our impairment can be cured. I as a child I already had accepted my impairment. But when you are adult and when somebody points towards your disability, they...erm...People never pointed out my disability because my mother always said that ‘you can do what you want to do. You know you are not disabled’ and she kept saying that to me. So I don’t feel like I am disabled.

In Chapter 4 (see 4.2.2) it was discussed how the Malaysian society has a strong belief in the traditional medicine and is heavily dependent on it. This was not surprising as disability is perceived as a ‘spoiled identity’ and people do not want to be associated with it. Therefore Murni’s mother ‘protected’ her from embracing a disabled identity and challenged the cultural conception that viewed disabled people as ‘weak’, ‘dependent’ and ‘pitiful’.

Likewise, Azni who was born with an impairment, was also taught by her family to have the same expectations as non-disabled children:

> I never felt that I was disabled […]. My father and mother placed emphasis on my studies […] My father went to school and informed my teachers not to treat me like a disabled student. He wanted me to be like other kids and be independent as if I was not disabled. That's why I studied hard and always got good results at school.

The attitudes displayed by Murni and Azni's family informed them that their impairment was not a barrier for them. They were told that they were capable of doing things and that they should not use their impairment, or let others use it, as a reason for stopping them doing something. This had a positive impact on their identity formation so that they never felt that they were 'disabled' and refused to be associated with a disabled identity. Thus, their attitude was one of self-affirmation and they excelled in education.

This was an important distinction in these women's identity formation. Chapter 4 revealed how many women faced structural and attitudinal barriers in pursuing their education. They received little support from the welfare state and some of them were also bullied by their friends at school. Parents did not want their children to be exposed to such disabling attitudes and disadvantages at school. They acted as 'buffers' against such disablism (Thomas, 1998) being imposed upon their children. They constructed a 'protective capsule' (Goffman, 1968) to prevent their children feeling stigmatised and discriminated against and from being labelled as 'different' from non-disabled children (Patel, 2002). Therefore such disassociation from a 'disabled identity' helped the women to have positive identity at school.

In addition family atmosphere, as opposed to inter-action within the public sphere, could serve to 'protect' a disabled child from taking a 'spoiled identity' as 'disabled'. Nani who had two disabled brothers never felt that she was disabled within her familial environment:

> I don't know, sometimes when I am with other people, I feel inferior to them. But when I am with my own family at home, I never felt that I was disabled actually. I felt nothing different although my family is a

> disabled family. So, we talked like usual, we laughed and did ‘normal’ things together.

Identity is a social role and it is learnt through social interactions with others. In her familial environment, Nani was not reminded that she was disabled and thus she forgot the fact that other people perceived her as ‘disabled’. It was an absent-presence of her identity construction as ‘disabled’. Therefore identity was not static; it was dynamic and reflexive as it could be varied in different contexts and spaces. Likewise identity could also change over time as is discussed next.

7.3.2 Changes over time

Whilst social interactions influenced the women’s identity formation, bodily changes resulting from different levels of impairments and ageing also played a vital role. This notion of change in the identity formation observed how women negotiated their bodily changes over time through different levels of experience associated with their impairment and age.

It was observed that different levels of impairment caused significant changes to bodily function, and affected how the women viewed themselves. For example, Wei Yin who previously refused to be identified with a ‘disabled identity’ by her Science teacher (see section 7.2.1), started to change her perception towards her functional role after being involved in a road accident:

> In 1999 if I am not mistaken, I met with a motorcycle accident [...] I spent half a month in the hospital and 8 months at home. After that, my leg was completely weak and it needed to be supported. At that time I needed to find a car, only then I realised about the Department of Social Welfare [DSW] [...] Then, I remembered what my Science teacher told me before about being registered with the DSW. At that time I never felt that I was disabled and then after the accident I felt it was difficult to move around. Now, I know how it feels to be disabled and I should have registered earlier.

Although she previously ‘dismissed’ her impairment, the significant changes in her body became ‘barriers to doing’ (Thomas, 2007) and it made her aware of her disability identity. It was observed that the low level of ‘impairment effects’ that she experienced previously made her less likely to be identified as disabled and vice versa. Nevertheless for Alice Chong, her second (hearing) impairment that she acquired after her first (mobility) impairment caused her greater internal distress than before:

> Now I struggle for my ear you know. When I was small I didn't know that my leg's problem would affect my eardrum. I got a ruptured eardrum. I have had several operations but still can't fully recover. Now almost a year after the last surgery and I still can't hear properly especially in noisy environments although I got a hearing aid. I feel upset because I have difficulty listening to what other people are saying and I can't tell them that I have problem with my ear. It's difficult you know to let people know about it. I don't want them to say that I am deaf it's so hurtful you know. So I really struggle now with my hearing defect and I feel so upset.

Living with multiple impairments intensified Alice Chong's experiences of disability. In 7.2.1 it was discussed how she was identified as 'disabled' by her friends and strangers because of her visible (mobility) impairment and this made her felt 'discredited'. This identification process emanated from 'outside' and not from 'inside'. Goffman (1968: 14) differentiated between people who are 'discredited' (people who are unable to conceal their stigmatising feature such as those with visible physical impairment) and people who are 'discreditable' (those whose stigmatising feature is not visible such as people with epilepsy). The 'discreditable' people can choose to 'pass' as 'normal' by concealing their impairment. In this respect, Alice Chong chose to 'pass' rather than being identified as a 'deaf' person but this brought significant psychosocial barriers to her. By concealing her hearing impairment she had difficulty interacting with others, and if she disclosed her aural challenges she would be subjected to 'multiple stigma' as a 'disabled person' and as a 'deaf person' - something that she did not want to be associated with. As a consequence this created a constant dilemma about her concealment and disclosure that made her feel highly 'vulnerable' (Lingsom, 2008) in her social identity. Therefore the varying levels of impairments could affect women's identity formation and brought significant psycho-emotional consequences.

The second form of bodily change that influenced how the women identified themselves was ageing. As the body changed along with ageing so identity changed. Murni, who was taught by her mother that she was not disabled and refused to be identified with disability identity (see 7.3.1), started to change her outlook on herself after encountering the effects of ageing:

> [...] So, at this old age, due to Post-Polio syndrome I started to feel that I am disabled.

Murni spoke of how she felt affected by her bodily changes that made her more aware of her impairment. She felt that her functional ability was deteriorating and this resulted in her experiencing greater mobility issues when she entered middle age. She was no longer able to walk or drive a car for a long distance as her legs muscles had weakened and this forced her to incorporate disability into her identity.

Similarly Jiaying, who also acquired Polio at the very young age, uttered:

> I am worried about my quality of health […] my movement is not like before. Although I can't be like 'normal' people, I still can move around 'normally'. But, now with this pain I feel worried as I am alone. I didn't expect to experience this pain so soon. I didn't expect it at all. Now, I feel so much difference as compared to last year. I am worried about living in a wheelchair.

As Watson (2012b) argues, changes in impairment associated with ageing might influence changes in identity. The increasing restriction of mobility and the pain associated with impairment that resulted from Murni and Jiaying's ageing, influenced their disability identity development. They felt disadvantaged as they grew older because 'ageing is particularly associated with increased levels of impairment' (Shakespeare, 2014: 87) and with physical and functional disability (Sidiah, 2008; Noran et al., 2010). Thus ageing effects had intensified their disability experience, changing their sense of self from non-disabled to disabled.

7.4 Resisting the label of 'disabled'

Despite the significant challenges encountered by these women in constructing their identities that caused them to experience psycho-emotional disablism, not all women simply became passive victims of stigma, prejudice and discrimination in society. Many of them exercised agency and resisted. Many vowed to prove to society that they could be independent beings and many others became disabled activists. This section will show how many of the women interviewed fought the negative stereotypes shown towards them and resisted being passive recipients of this form of disablism.

7.4.1 *'Being by doing'*

This section examines the ways in which the women interviewed exercised their agency and proved to others that they were 'able' and not 'disabled'. Zahra for instance illustrated how she was able to overcome her fear and anxiety in dealing with oppressive social interactions with others:

> I don't want to burden people around me. I no longer want to trouble my friends, I don't want [that]. I know that I burdened them so much and I know that my impairment brought difficulty for them. I am a troublesome person. But now my dream is just to be independent. I want to do many things by myself regardless of what people say. Although some people will say that I can't do it, but it doesn't matter. What is important is myself and I know who I am. I will no longer listen to what people want to say about me. It will not prevent me from doing what I believe I can do. Previously, I always cried. I was very sensitive, I couldn't you know. Even on small things I took it seriously. I would keep it deep in my heart and it burdened me. But now, I take it as a challenge and I don't care what people will say. I don't mind if people want to say that I am troublesome to them, I don't care! What is most important is that I want to change myself. I want to be independent and show them that I can do it. That's the only dream I have now.

Whilst Zahra took the societal oppressive attitudes towards her as a challenge, Azni was angry when people underestimated her abilities and struck back to show them that she was an able being:

> We have to be strong and never assume that we are disabled. If we think that we are disabled then we will become weak. We must assume that we can do anything like other people. My spirit is like that. I don't like people calling me 'handicapped' and [saying that I] cannot do anything. If people say that I will become angry and I will fight back!

Likewise Imah determined to prove herself through employment:

> For me, Malaysians normally have the mentality that thinks disabled people cannot go far like 'normal' people. Like in employment, no matter how educated we are, people will always see our physical disability. I am frustrated that when I went for interviews, they always

> saw my physical disability more than my abilities. I want to prove to society that I can be a good worker if they give me an opportunity […]

These women not only proved themselves in employment and by doing things independently, but they also developed a positive identity after gaining their own transport and thus becoming more independent:

> You know that it's very difficult to move around with a wheelchair. I can't take bus because it's not accessible at all. Taxi drivers also don't want to take me with so many excuses. I can't depend on my family because they are also busy with their own business. I felt so frustrated that I can't be independent. So, I decided to buy a [disabled] motorcycle [...] When I have more money, I bought a car [...] It's easy when you have your own transport that you don't have to depend on other people (Eryna).

For Nadia, she resisted the label of 'disabled' by being a wife and a mother:

> I never thought that I would get married. Even if I got married, I thought that I would marry a disabled man like me. I never expected that I would get married to my husband who just has a speech problem, unlike myself, in wheelchair. I feel so blessed by God that now his family can accept me after I delivered my baby. I also feel good about myself that I can give him a son [she was also expecting her second child] and a grandchild for his family. You know that two of his brothers got married to non-disabled women, they don't have children yet although they have been married for a few years. So, I feel good that although I am disabled I can have a baby.

Nevertheless for some women their constant struggle for self-recognition in society brought unbearable emotional fatigue causing them to experience psycho-emotional disablism (Thomas, 2007; Reeve, 2012):

> I have always known myself as a disabled [person]. I don't know whether it's my mistake that I want to prove to society that I am not disabled. But at the same time people take advantage of me […] So, I find that I am wrong. I am wrong. I want to give up my hope. I don't want to live in my dreams anymore. I want to give up […] No matter how hard we try to prove to people that we want to change our lives, it will not work. Disabled people will always remain disabled. We will always be disabled. You get what I mean? (Alice Chong).

This had profound impact on Alice Chong's identity formation and made her develop low self-esteem that influenced her personal and public life, especially in her relations to others. Therefore this section demonstrates how many women proved that they were not passive victims of disablism and proved their agency in society. However such resistance can lead to emotional fatigue and psycho-emotional disablism if efforts to foster physical and social support for these women is lacking.

7.4.2 Disability activism

Despite the fact that many of the women experienced disablement and psycho-emotional disablism after being exposed to prolonged oppression and discrimination in society, a number of them managed to recover from these challenges and claimed a political identity. They self-identified as disabled activists and associated themselves with disabled people's organisations. They continued to resist all the stigmas, prejudices, and discriminations against them in society and became determined to help other disabled people. Of the 33 women interviewed; ten of them were involved in activism, four were Malays, three were Chinese, and another three were Indian. Some of them became full time disabled activists - running disabled people's organisations or working for them, whereas others were helping disabled people (women) or disabled organisations when they could. This section will explore the different roles these women took in building their capacity and exercising their agency in disability activism undertakings.

All these women had their own disabling stories but managed to overcome those challenges and achieve success in their lives. This was characterised by individual strengths and collective identities. Pushpa, who was divorced by her husband immediately after she became paralysed (see Chapter 6, 6.4.1), represented the best example of how women turned their personal identity as a disabled person to a political (public) identity as a disabled activist:

> After the accident, I spent almost a year on my bed in a nursing home [run by her sister]. At that time I was so depressed because I had lost everything. My husband kept being pressured to divorce me. I was crying and crying every day. When I looked around, I saw many people who are old and dying. I thought that I am going to be like them. My life is practically over. My sister always came and motivated me to start a new life. But I never bothered her. I thought that I'm going to spend my whole life here. Then, one day [after a year in the nursing home] I decided to go out by myself. I called a taxi and went to a

> shopping mall alone [...] I saw a couple who were both in wheelchairs at the shopping mall. I thought if they can live happily in wheelchairs why not me? Since then, I decided to start my life all over again and I wanted to find my own happiness [life partner].

Pushpa regained her self-esteem and subsequently led an independent life. She became actively involved in many disabled people's activities and organisations and later met her current husband (also disabled). They decided to run an independent living organisation for disabled people and have helped many disabled people acquire the basic skills for leading an independent life. She managed to overcome her own fear towards her impairment, challenged the negative cultural conception of disability identity, and emerged as a political entity; inspiring many others who lived with impairments.

The data revealed that there were two different types of activist roles exhibited by these women: 'passive roles' and 'active roles'. It is important to make this distinction within Malaysian political (activism) scenarios. Of the ten women who claimed that they were disabled activists, three of them employed 'passive roles' in their activism activities. All of them were working full time as civil servants (in the governmental agencies) and had less time to spend in disability movements and activities. Instead their participation was restricted to any spare time they had. As Murni related:

> In a way I'm an activist. Definitely I am activist but I have other things to do as well. What I did was in my spare time which is not much we create documents to enhance public policies for disabled people […]

Among their major roles were helping disabled people's organisations or disabled people, and assisting the government on issues pertaining to disabled people, especially in documentations and campaigns. However they never got involved in direct and confrontational action such as demonstrations or strikes against any parties. Their capacity as civil servants restricted their roles as activists. In Malaysia those who are employed by the governmental agencies are prohibited from being involved in any political or confrontational activities (CUEPACS, 2008). They are also prohibited from making any anti-government statements or expressing their personal dissatisfaction and opinion in the media (Public Service Department of Malaysia, 1993).

For example Rupa expressed her personal thoughts regarding her role in a disability movement:

> For me I am fine getting involved with my [disabled people] organisation's activities like hanging out with disabled peers, doing documentation works and attending seminars and sport activities. But I am not one to attend [street] demonstrations like that. I am supporting my friends choose that cause but I will never do that by myself. And as a government servant, I can't do that otherwise I will get caught.

In Chapter 1 it was discussed how women's rights activists have been detained without trial, arrested for charges of 'unlawful assembly', and charged for 'maliciously publishing news' (NGO Shadow Group, 2005; Women's Aid Organisation, 2012). Such political restrictions on women's activists hindered effective participation of disabled women, especially those working with the government, in political movements. Whilst these women had limited opportunity to exercise their agency within disability movements, they still managed to play their roles, albeit passively.

The other type of role exhibited by the majority of disabled activists was 'active role'. As described by Cornie Tan:

> Previously, I came to live in this centre to learn a language course after I dropped out of school. Then, several years later after I finished my course, I started to work here. Since then, I helped to run the centre and became one of its administrators. We always organise campaigns and public demonstrations to create awareness among people. At the same time we demanded effective actions from the government to cater for our needs especially in public transport. We had many dialogues with the local authorities to tackle this issue but still it remains unresolved. I also attended many seminars about disabled people, especially for disabled women. You know that disabled women are among the disadvantaged ones. In this centre I am responsible for looking after the disabled women and we have organised some programmes for them. It was sad that many disabled women were physically and emotionally abused by their spouses. Some of them were also exposed to sexual abuse in the villages and by taxi drivers [...]

It is through collective disability (political) rights' struggles that some people find their strength to resist (Shakespeare, 2006; Thomas, 1999) the daily stigmas, prejudices and discrimination towards disabled people in society.

Cornie Tan not only benefited from such a disability rights movement but she was also empowered to cater for the needs of disabled women through various programmes and strategies that she initiated with her organisation.

Although the women were able to exercise their active roles and participate in disabled people movements, some of them were restricted by the 'male dominated' political movements. For instance one woman described:

> Yes disability, the disability world. And then even disability movements have politics you know. Some people dislike me, and some people dislike that person and this person like that. A lot of erm you know that everybody wants power. And then sometimes because I'm a woman and I'm [an ethnic group[16]], I'm a disabled also. This one you know [an ethnic group] guy, disabled guys give me problems. It is I don't know why *lah*. Sometimes the [an ethnic group] community, I mean not that I'm putting down my own community. But I don't know. The envy is terrible [...] They are very good at discrediting me until I take lawyer's letter. Then one of the guys threatened to come to beat me up at the house [...]

This participant perceived that her gender identity as a woman with impairment had exposed her to 'male dominated' attitudes in disabled people movements. As discussed in Chapter 1 women are more 'vulnerable' in political participation and they have less representation in public lives because of oppressive attitudes held by men. Women in Malaysia are perceived as 'weak' and have less voice than men and as such this woman was subjected to oppressive treatments by male disabled activists. Such oppressive attitudes towards women could limit effective participation of women with impairment in disability movements. This is therefore an important point in addressing gendered experiences in disability activism in Malaysia. Disabled women, like the one mentioned above, perceived that they were not only disadvantaged as disabled but also because they were women. Nevertheless such negative experiences did not stop the woman discussed above from fulfilling her determination to help disabled people, especially disabled women, as she was inspired to be a disabled senator:

> I want to be a senator to fight for the rights of disabled people. I don't know whether I got the point or not. I don't know [...] I want to be a senator to be able to serve. You know to speak up. You know because sometimes you need to have some position or standing for them to

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[16] The participant's ethnic group was concealed to protect her identity.

> listen. Yes for them to listen. People say that all NGOs all say the same things. My government doesn't listen. Really frustrating you know. That's why I want to become a senator to represent disabled people at the national level.

She perceived that disabled activists within the NGO movements have less power than those within the government. Therefore, she was determined to become a disabled senator to gain wider access to disability activism. In December 2007 the Malaysian government appointed the first disabled senator, Prof. Datuk Dr. Ismail Md. Salleh, who was born blind, to represent disabled people in Parliament (Utusan Online, 2007). After his demise in August 2009 no one was appointed to replace him. However in October 2013, the Women, Family and Community Development Minister announced that a disabled senator will be appointed soon (Lee, 2013). This is a good indication that the Malaysian government acknowledges the need for representation for disabled people at the state level and to promote the positive disabled role model in society. Hence disability activism played an important role in constructing a positive aspect of identity formation for disabled people in Malaysia.

7.5 Identifying disability with religion

As discussed in Chapter 1, not only is Malaysia multi-ethnic it is also a religious society. Although the official religion is Islam and 60 percent of the total population are Muslims, other religions such as Buddhism, Christianity and Hinduism are also practised by the people (Kamal Hassan, 2005). Analysis Chapter 4 observed how religion and traditional rural beliefs influenced Malaysian attitudes towards traditional medicine and thence disability. Chapter 6 also discussed how religion played an important role in women's relationship experiences. This section explores how religion continued to play vital role in the women's identity formation. The data revealed that the majority of the women interviewed, regardless of their religion, constructed their disability identity around religion and God. These women always made reference to their religion when talking about their disability experiences. The majority of them had a positive attitude towards their disability identity which closely linked to their religious belief. Thus religion appeared to have a key role in shaping the women's identities. This linkage was also found by Zoebia Islam (2008) in her study on young Asian disabled people in the UK.

Whilst the majority of women associated themselves with an ethnic and religious identity, their religious identity was more apparent than their ethnic identity in defining their disability experiences. Among the women interviewed, all Malays were Muslims; the majority of Chinese were Buddhist, except two who were Christians, and the majority of Indians were Hindus, except two who were Muslims and one who was Christian. As discussed there are many examples of how the women were identified as 'disabled' linking them to 'spoiled identities' and exposed them to stigma, prejudice and discrimination in society. Such oppressive attitudes undermined their physical and psycho-emotional wellbeing and affected their identity formation. It was observed that, because society was so oppressive towards them, the only way to overcome such psycho-emotional damage was only through religion - as this section will show. From this three main themes emerged from the participants' identification of their disability experiences with religion: disability as a 'destiny' from God, disability as a 'blessing' or as a 'punishment', and denial of access to religious practices.

7.5.1 Disability as a 'destiny' from God

The majority of Muslim women interviewed perceived their disability as a 'destiny' (predetermined or inevitable fate) from Allah (God), which had to be accepted in a positive way. Most of them believed that there was wisdom (virtue) behind it. They believed that Allah had chosen them to experience disability and they needed to keep praying and to think positively. This was described by Nani:

> We cannot always think of our limitations [...] I believe this is my destiny from Allah, maybe this has been taught by my family since I was small [...] When we think about it, every single thing that happens, there must be a wisdom behind it.

For Azni, her 'destiny' as disabled person did not stop her striving hard:

> If I want something, I will do my best to get it [...] It is not our will to become disabled but Allah gives us it. But He wants us to strive hard; if we don't work hard we can't get what we want.

Azni and Nani both had a strong identity as Muslim women and shared similar thought processes and understanding about their disability, along with the majority of Muslim women interviewed. In Islam, through the excerpts from the Qur'an and Hadith, impairments are viewed from a human rights perspective (Ali, 2008), impairment is considered as morally neutral (Bazna and Hatab, 2005) and thus Islam emphasises on the concept of equality of all human beings (Ali, 2008).

> Qur'an concentrates on the notion of *disadvantage* that is created by society and imposed on those individuals who might not possess the social, economic, or physical attributes that people happen to value at a certain time and place. The Qur'an places the responsibility of rectifying this inequity on the shoulder of society by its constant exhortation to Muslims to recognize the plight of the disadvantaged and to improve their condition and status (Bazna and Hatab, 2005: 5-6, emphasis in the original text).

In view of this Islam does not disregard people with impairments, and places responsibility on society to cater for the needs of disabled people. Nevertheless in reality many of the women interviewed were 'disregarded' through their status as disabled persons in Malaysian Muslim community. As a result they diverted their dependence on society to a dependence on God - to help them 'escape' from societal inequalities.

A similar attitude was also displayed by Buddhist women, as Wei Yin articulated:

> Yes, it is difficult being a disabled person. But what else can we do? We can just pray to God to help us [...]

Although it was hard being a disabled woman Wei Yin accepted it positively and believed that God would help her. Buddhism teaches that human life involves suffering and it is inevitable. It 'suggests that suffering decreases and healing increases when we let go of wanting things to be different from how they are and instead move towards an acceptance of what is available in the present moment' (Schumm and Stoltzfus, 2007: 11). However people are prohibited from dismissing those with illness and impairment, saying they should be respected. Buddhism also emphasizes that suffering can be only minimised by turning greed into generosity, anger into loving-kindness, and delusion into wisdom (Schumm and Stoltzfus, 2007). Those who are impatient or angry at pain, illness, or disability, do not promote their healing. Therefore the Buddhist women perceived their impairment as something ‘predestined’ by God and believed they should tolerate their sufferings in spite of societal inequalities.

This ‘helpless’ belief was also shared by Hindu women, as Shanti described:

> I don’t have anyone. There is nothing that I can do except pray and do good deeds. I can only pray to God that He will help me. He will help disabled people like me (crying).

In Hinduism the law of karma dominates the basic principle of human sufferings and misfortunes. According to the Hindu law of karma (karma-phala) someone’s deeds in a lifetime will have consequences in the current or subsequent lives that are linked to the belief in reincarnation. Good deeds will bear good outcomes and bad deeds will carry bad consequences. Someone’s misfortunes may be the result of bad karma (bad deeds) which were performed in the present or in a past life (Yamney and Greenwood, 2004; Vidya, 2011). However fate and karma are two different things but intertwined where fate relates to God and karma to man (O’Flaherty, 1980). ‘Fate can be changed by offering prayers and propitiations to God for grace and mercy whereas *karma-phala* can be changed by performing good deeds and acts of piety’ (Vidya, 2011: 74, emphasis in the original text). Although Shanti and other Hindu women did not mention that their impairment was as a result of their bad karma, they plainly accepted their disability and strived to do good deeds in their lives. As a consequence people who believe in the Hindu law of karma may regard disabled persons as possessing a ‘bad’ identity and as such they may have negative perceptions and attitudes towards them.

The ‘helpless’ attitude towards disability experiences with a strong linkage to religious beliefs was not only upheld by the Muslim, Buddhist and Hindu women but also by the Christian women, as described by Cornie Tan:

> Everything I leave it to God. If God gives us good things then we accept it [...] we leave it to God because I believe that later everything will be OK. Thanks God [...]

Writings in the *Disability in the Christian Tradition* highlight that disabilities do not define a person but that the worth of the human person lies in the grace of God (Brock and Swinton, 2012). Respecting this representation, the act of loving and caring for others should be in the foreground and based on the teachings of Christ and this opposes the cultural assumptions of what counts for 'normalcy' (Reynolds, 2013). It means that one is defined under the 'Word of God' or the 'grace of God' and what matters is the person, not his or her disability. Moreover Reynolds asserts:

> Behind the fleshly signs of disability lies a hidden value [...] this dismisses the bodily differences and vulnerabilities that shape us and make us who we are [...] this trivializes the experience of disability, it can valorize suffering as a vehicle of redemption and/or moralize disability as in reality something positive, either for oneself or for others (a kind of spiritual lesson) (Reynolds, 2013:292).

Based on the Christian Tradition, impairment is not viewed as something negative, but as having a positive value for one's spiritual insights. Accordingly Christian women, as articulated by Cornie Tan above, perceived that disability carried positive values from God and they believed in that.

The above examples have shown how disability was viewed in Islam, Buddhism, Hinduism, and Christianity, and how the women interviewed developed their disability identity around their belief in God and religion. In fact all religions treat impairment as something positive and believe that one should not be discredited, although an exception can be observed regarding some aspects of the law of karma in Hinduism. In light of this religious insights became an important source of the coping strategies for many of the women interviewed working as a means to accommodate the negative cultural conception of disability in Malaysian society. Johnstone et al. (2007) in their study also found that religion and spirituality were used by many participants in a similar manner for their impairments and furnished new meaning for their lives.

7.5.2 Disability as a 'blessing' or as a 'punishment'?

As discussed above, many of the women incorporated religious insights into their understanding of disability experiences. They not only perceived their impairments as a 'destiny' determined by God but also as a 'blessing' that should be embraced and celebrated. Many of them did not see being ‘disabled’ as an obstacle but they accepted their disability as God’s challenge to lead a better life. For example, Manisah and Norshidah (2008) conducted a study on a group of Malaysians with special needs and found that the majority of their participants held the same perspective. However some women had a negative perception; seeing their disability as a ‘punishment’ from God, as this section will explore.

Nisa, a Muslim woman, expressed her gratitude for her impairment but felt irritated with societal disabling attitudes towards her disability:

> I feel blessed although I am disabled I still can do many things like other people. It just that sometimes, I am angry with people surrounding me, they can’t accept me as disabled. They knew nothing about our life as disabled.

For another Muslim woman Fatin, her impairment did not only make her feel blessed but it also increased her religious belief and rituals:

> I have to be strong. How to say ya? I have to be strong spiritually. I cannot become weak. I have to preserve my *iman* [belief]. For example I cannot leave my daily prayers, always remember Allah, am always reciting Quran and *dhikr* [remembrance of Allah]. So it makes me feel better and grateful as a disabled person.

Fatin found her strength to triumph over her disability experiences through her faith in religion (Thomas, 1999). This can be related to the concept of a ‘test of faith’ in Islam. Early and late Muslim scholars explained that disability may be interpreted as a test by God to His servants’ faith. People are tested with various difficulties, pain and pleasure to establish their obedience to Allah and on the basis of such tests; people are admitted to Paradise or Hell in the hereafter (life after death)[17]. In this regard, those who accept the test of faith of living with disability positively and stay steadfast in their religion are believed to be blessed with eternal happiness in the hereafter (see Mohammed Ghaly, 2010: 47-51).

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[17] In Islam the concept of the existence of life after death is central to the doctrine of Quran (ReligionFact, 2013). Muslims believe that the present life is a trial in preparation for the next realm of existence – the eternal life after death (the Day of Judgment). In the Day of Judgment, God will attribute His Justice and Mercy based on human deeds in the worldly life (Abu-Harb, 2002).

On the other hand, a Muslim woman held a different perspective in which her impairment was believed to be a form of punishment for her mother's supposed 'wrong deeds' during pregnancy:

> My mum told that when she was pregnant of me, she went for rubber tapping. But I can't remember she was pregnant for how many months at that time. She felt like eating grasshopper at that moment. She caught a grasshopper, tied its legs and put it in a covered tin. However, she forgot to bring it back home because she was busy tapping the rubber trees. The next day when she looked for the grasshopper, it was already dead. Then, I was born with impaired legs just like the grasshopper. But I'm not really sure maybe it's true. Well you know that during pregnancy we can't do bad things to insects or animals (Intan).

Such belief was perceived to be rooted in cultural belief rather than religious belief as Rispler-Chaim in her study of *Disability in Islamic Law* says:

> It is never proclaimed that the disease is predestined by Allah so that the ill Muslim has an opportunity to repent, or the disease is a way of punishment for certain sins. Nowhere in the Quran, Sunna or fiqh is a clear causality established between Allah and the onset of a disease and/or disability in a believer (Rispler-Chaim, 2007: 7).

Some Muslim scholars supported the above statement that refused to see a link between sin and punishment (the infliction of pain). However the statement remains deliberately contradictory to Quranic texts and Sunna of Prophet Muhammad (peace be upon him) in which for example, more than one Quranic verses supported the link between sin and infliction of pain. Mohammed Ghaly asserts in his book of *Islam and Disability* that disability may be, but need not necessarily be, the result of committing sins and people cannot be afflicted with disabilities as a punishment for sins committed by others (Mohammed Ghaly, 2010: 42-45). Therefore Intan's suggestion that her impairment was a punishment from God for her mother's sins might be linked to cultural belief, or religious belief, or both. However this did not negatively affect her identity formation because she did not perceive herself as the same way society perceived 'disabled people', as she felt she was no different from others despite her impairment.

The negative association of disability with religion was also held by a Buddhist woman:

> That’s why I feel that God wants to ‘destroy’ my life huh [...] to struggle for this. I don’t know when I’m going to have a happy life. Sometimes, I see other people living so happily (sobbing) but just to console myself, when I compare myself with other disabled people here [a sheltered employment for disabled people] I feel much better than them (Alice Chong).

This perspective can be linked directly with the concept of suffering in Buddhism as discussed in 7.5.1. Whilst having expressed negative attitude towards her impairment as ‘destruction’ from God, Alice Chong developed more positive feelings towards it by comparing herself with other disabled people who were more disadvantaged than her. This supported the findings in 7.3.2 that observed how many of the women developed a positive attitude towards their disability identity after coming into contact with other disabled people. Nevertheless, the majority of Buddhist women saw a positive association between disability experiences and a ‘blessed life’ as described by Jiaying:

> [...] at this moment, I am more into reading books, more into religious books about Buddha. It tells about philosophy as a human and about life. I am inclining to that kind of book. When we understand more about the philosophy of life, about humanity, then we become more grateful. I feel more blessed than many other people in this life.

Similarly Christian women viewed their disability as a ‘blessing’, as Amanda Chan said:

> I am grateful of whom I am today. And one thing if you ask me, I’ll tell you one thing. If I never, didn’t had my accident and being disabled person, I don’t think I treasure and I appreciate so much of my life. Because of my disability, now I really appreciate and thanks giving for what I am today because that is a mission for me to do. Last time when I first get accident, I always ask God. Why me? I attempt suicide twice. But I believe God tell me that time not your time yet. You have to stay. I stay. Because I haven’t accomplish my mission. That’s why I am where I am today. That’s why last time when I’m out of the hospital and I refuse to go back to X [a state in Borneo Malaysia] because I don’t want to be another OKU [disabled people], another ‘handicapped’ staying at home doing nothing. Not productive, not, you know either one. Even my father tells me, ‘never mind, you don’t have to work. I buy a big TV for you, buy video for you. You can watch video every day’. That is not the life that I want. To me, I want a life that is beyond what general people think what I can be.

These women were also felt more aware of their disability identity when they encountered structural and attitudinal barriers within a religious context as discussed next.

7.5.3 Denial of access to religious practices

Chapter 4 touched on the structural and attitudinal barriers at home and in educational, employment and public settings, and this was also apparent in religious settings as this section explores.

A Muslim woman Nisa related how she was upset by the attitude of people towards her impairment in the mosque:

> Sometimes, I felt disappointed with our people's attitudes. You know that at times when I went to mosque with my wheelchair, some people said that I can't enter the mosque with my wheelchair because it will make the prayer places dirty [with her wheelchair tyres]. I felt so insulted by them. It was not easy to find accessible mosque without steps, even then they made such comments that really disturbed me. That's why I rarely went to mosque [...]

The structural and attitudinal barriers at places of worship made her aware of her impaired body and this prevented her from performing her prayer at mosques as she desired. Both the direct (attitudinal barriers) and indirect (structural barriers) psycho-emotional disablism (Reeve, 2012) that Nisa experienced at mosques prevented her from 'doing' (Thomas, 1999) her obligation in Islam and prohibited her from 'being' (Thomas, 1999) what she perceived as a 'good Muslim'. As such these served to undermine her sense of self and her psychological wellbeing as a disabled Muslim, causing her to experience psycho-emotional disablism (Thomas, 2007). Zoebia Islam (2008) also found in her study that some young disabled Muslims were denied access to religious teaching because of their impairment.

This attitude is argued to be not rooted in the Islamic teachings. The inclusion of all people regardless of their ability is strongly encouraged (Wan Arnidawati, 2013) and Islam places emphasis on the responsibility of society to assist disabled people (Hiam et al., 2012). The Prophet Muhammad (peace be upon him) gave examples of how people with impairment should be treated. In one extract, a blind follower asked Prophet Muhammad (peace be upon him) for a clarification on his teachings but he turned away and Allah directly criticised the Prophet's impoliteness through Quranic revelation (Wan Arnidawati, 2013). Also there were many examples where people with impairments were employed and appointed with highly prestigious jobs in Islamic society such as *muezzin*[18], prayer leader (imam), judge and head of state (Mohammed Ghaly, 2010). According to Islam disabled people should be treated equally and with dignity. Thus it suggests that the negative attitudes displayed by Muslims towards Nisa can be linked with the negative cultural conceptions on disability and not those based on religious doctrine.

A Hindu woman also experienced a discriminatory treatment when performing her religious rituals at an Indian wedding:

> **Deepa:** There was one time I went to a wedding. You see in our culture, you know when we bless the couple, in the wedding ceremony; we put the thing
>
> **Me:** *Thali?*[19]
>
> **Deepa:** Ah yes *Thali* [a wedding necklace] around the bride. We have to throw the blessing rice coated with turmeric powder and all that isn't it. So, before they carried out the blessing rice for people to bless, they put a coconut and they chained the *Thali* around there. Then with all the rice for people to bless and you pick up some rice then you keep the rice. So there was this lady, it was a friend's wedding you know. She brought [the rice] she didn't bring any to me because I was in a wheelchair. It was so obvious *la*. I just gave her a look. Whereas I mean other weddings that I have been to, my cousins' weddings, I've never been treated [like this]. It was the only experience I had like that. So she [might] think that I am a bad woman or negative like that. That's why I should not be blessing the couple. Yes it reflects her erm...
>
> **Me:** Thinking?
>
> **Deepa:** Yes.
>
> **Me:** On you?

---

[18] A *muezzin* is the person designated to pronounce prayer time in Islam by chanting a special religious formula called *adhan* (Mohammed Ghaly, 2010).

[19] A *Thali* necklace is a necklace that is given in Indian culture or religion by the groom's family to the bride, usually in place of a wedding ring.

> **Deepa:** Yes. On me and on disability.
>
> **Me:** Erm...so how do you feel about that?
>
> **Deepa:** At that moment I felt offended. So offended with such an attitude towards me.

Such negative attitudes as those displayed towards Deepa can, once again, be linked to the concept of bad karma in Hinduism that perceives that those who suffer misfortunes have performed bad deeds in the present or in a past life (see 7.5.1). Disabled persons like Deepa might be perceived as bad individuals or as having negative attributes. This could be linked with Goffman's ideas on 'spoiled identity' that dominate the cultural conception of disability within Malaysian society. As a consequence such prejudicial and discriminative attitudes had a negative impact on disabled women's identity formation. They were not only perceived as having a 'spoiled identity' in daily encounters with others but also in cultural-religious practices.

Once again the structural and attitudinal barriers extended to religious spheres and hindered these women's rights to equal opportunity when performing religious practices. Their 'impairment effects' (Thomas, 1999; 2007) and the societal oppressive attitude towards them determined how far they could adhere to religious practices. This significantly undermined their spiritual needs to perform their religious rituals in the way they wanted. This section has uncovered how women constructed their disability identity around religion and God. This aspect of identity is important in understanding how Malaysian disabled women were identified by others and how they viewed themselves. Religion became a key aspect in their identity formation because religion is strongly embedded in Malaysian society. For many of them, religion gave them hope and strength to overcome their disability experiences and as such they embraced their disability identity positively despite daily oppression and discrimination.

7.6 Conclusion

This chapter has shown how the women's identity formation was strongly influenced by their social interactions with others and the societal conception of disability. It was apparent that Malaysian society possessed a negative cultural representation of ‘disabled people’ that linked directly to Goffman’s notion of ‘spoiled identity’. Many women were identified as ‘different’, ‘weak’, ‘dependent’ and ‘pitiful’ at home, and in schools, workplaces, public places, and in all aspects of their lives. This was reinforced by the deficiency of state welfare system, the absence of positive disabled role models, and the way women were perceived within Malaysian patriarchal society. All these reinforced the negative cultural conception of ‘disabled people’ and disability that influenced how women with impairment were identified and formed their identities.

The findings demonstrated that these women had little opportunities for self-affirmation. This directly links with Thomas’ notion of ‘barriers to being’ and ‘barriers to doing’ that prohibited women’s full potential and prevented their full participation in society. They were also much more susceptible to experiencing ‘psycho-emotional disablism’ as a result of societal oppressive and discriminative attitudes towards them. Nevertheless some of the women exercised their agency and challenged the stigma, prejudice, and discrimination towards them through active participation in both the private and public realms.

Another important dimension in the identity formation of these women was religion. Many of the women developed their disability identity around God and religion. This feature could be found in women from different religions such as Islam, Buddhism, Hinduism and Christianity. The one common factor was that they had all used their religious identity to develop coping strategies. This might stem from the importance of religion in Malaysian society. It is vital to note that because society was so oppressive towards them, and the state failed to support them, the only way they felt able to overcome such disablism and disablement experiences was through religion. Therefore the majority of them developed positive attitudes towards disability which were rooted within their religious identity, although some of them were not.

Indeed being disabled women in Malaysia was difficult because they were constantly challenged to prove that they were capable of becoming active independent social agents in society with regard to their disability, gender, and religious identities. At the same time their identities were complex and reflexive and could change within different contexts, levels of impairments, ages, cultural and religious beliefs. In conclusion an integrative approach incorporating disability, gender, cultural and religious identities should be employed to gain a holistic understanding of disabled women's experiences in the Global South.

Chapter 8: Discussion and Conclusion

8.1 Introduction

This final chapter brings together the important themes that have emerged from the analysis of Malaysian disabled women's lives as discovered in the previous four data chapters. The findings demonstrate that socioeconomic, geography, impairment, gender, family, cultural and religious values all influence the disability experience in a complex manner. This chapter therefore outlines the major findings of the study, highlights important aspects of the research, and discusses some implications for theory, policy and practice.

8.2 Summary of findings

The thesis sets out to explore how women with physical (mobility) impairment in Malaysia experience their lives. Despite a significant number of disability research studies conducted in Malaysia, only a few focused on disabled women. For this reason the study aims to provide empirical evidence of how disabled women across three different ethnic groups in Malaysia experienced their lives. This summary therefore provides a brief review of the major findings of the study that not only discloses how Malaysian disabled women experience their lives but it also provides data for cross cultural research on disabled women in the Global South.

The data revealed that the majority of women were marginalised from wider social and economic participation due to multiple factors. It displayed complex interactions between intrinsic and extrinsic factors. The intrinsic factors included individual aspects such as the nature and hierarchy of impairment, personal values, attitudes and choices. The extrinsic factors involved structural barriers, poverty, rurality, family, gender relations, societal attitudes, culture, and religion. These were amplified by lack of disability welfare and support from the state, as well as gender inequality in Malaysia.

The findings disclosed that the majority of women interviewed were affected by two main factors in their experiences of disability – poverty and rurality. Their low socio-economic conditions; particularly their poor family background and residential location located far from cities prevented them from getting access to biomedicine. This was also reinforced by the lack of social care protection and a strong cultural belief in traditional medicine. There were significant interactions between the poverty, rurality and impairment. The low socio-economic status and geographical isolation increased the likelihood of developing impairment and/or amplifying the impairment conditions. Subsequently many women had little access to education, training and employment because of their impairment; as well as being subjected to structural and attitudinal barriers in society. Therefore poverty was revealed to have a positive causal relationship with impairment and vice versa.

The study found that the majority of participants received primary care and support from their family while some of them did not. Again the lack of disability support from the welfare state encouraged a strong dependency on family and thus undermined their agency. While the traditional notion of care provided by the family was important to many women, it was not without its cost. The strong reliance on family reinforced a high dependency on families that made the participants feel disempowered and subject to power relations within familial interactions. However some women were able to challenge such notion of disempowerment and proved their agency through domestic works and employment. It was also observed that strong traditional gender roles and gender divisions prevailed in many families across different ethnic groups in which women were regarded as the primary carer and confined to domestic works whereas men held more power than women. There was a dynamic interaction between individual agency and familial structure that significantly challenged the women’s autonomy.

Disabled women in the study continued to face constant challenges in their lives, including the right to a family life. Many women were restricted from experiencing love, marriage and motherhood at three different levels: the individual, the familial and the sociocultural. Many subscribed to traditional gender roles and gender divisions and as such it resulted in some of the women interviewed being subjected to male exploitation. Nevertheless barriers to family life involved complex interactions between individual and contextual factors that led them to experience constant dilemmas in forming relationships. The absence of an adequate welfare state made these women highly dependent on the family and consequently the family had greater control on them and were thus able to restrict their individual choices and autonomy in pursuing relationships. This was reinforced by the strong influence of cultural-religious norms that intensified their experiences of disability. There was an explicit influence of culture where women across different ethnic groups had encountered strong familial objections, either from their own family or their prospective partner’s family, to getting married to both disabled and non-disabled men. Nonetheless Muslim women had the least opportunity for a family life because of their strong adherence to religious principles as compared to the situation for non-Muslim women. The Malaysian norms which disapprove of having children before legal marriage added another layer to the barrier to family life. This implied that the unmarried women had little possibility of having their own children. Findings therefore showed that there was a complex intersection between individual and sociocultural factors that prevented these women from becoming partners, wives, and mothers.

The data also disclosed that the women interviewed encountered persistent challenges in constructing their identities; both in private and public life. These women were constantly challenged to prove that they were active independent social actors in their family, school, workplace, and in public. The absence of positive disabled role models in Malaysian society reinforced negative perceptions towards disabled women that undermined their potential in all aspects of their lives. This caused them to experience the significantly greater physical and psycho-emotional distress of having constantly proved that they were ‘able’ and not ‘disabled’. At the same time they were prevented from ‘being women’ due to strong social forces from the family and a society that ‘suppressed’ their femininity. Whilst many women ‘succumbed’ to the domination of a social structure that viewed disabled women as ‘different’, ‘weak’, ‘dependent’ and ‘pitiful’, some of them were able to challenge such notions of disempowerment through political activism and an independent life. Interestingly many women used their religious identity to adapt to their social oppression and disability experiences. It was clear that the women’s identities were complex and reflexive - influenced by different backgrounds, the nature and hierarchy of impairments, femininity, as well as cultural and religious domains.

The women interviewed were subjected to significant barriers and challenges which worked to preclude them from being included in their family and society and that this worked at different levels of the individual, the familial and the sociocultural. These three factors in some way or another influenced how these women experienced their lives living in a traditional patriarchal and disabling society. It involved multifaceted interactions between individual agency, socioeconomic condition, familial structure and sociocultural influence in understanding their experiences of disability. These multi-layered intersections of different factors posed a threat to women's wellbeing that undermined their sense of self and agency, both as women and as individuals. As a result many of the women experienced what is termed by Thomas (2007) as 'psycho-emotional disablism'. This notion of disablism, related to 'barriers to being' (ibid), restricted the women's full potential and autonomy as well as creating 'barriers to doing' (ibid) which in turn prevented these women's full participation in their families and communities. Nonetheless the psycho-emotional disablism experienced by the women in this study is more complex than that suggested by Thomas as argued in this thesis.

8.3 The link between poverty, rurality and impairment

Braithwaite and Mont argue that 'disability has often been associated with poverty, but few studies have examined the relationship empirically in developing countries' (Braithwaite and Mont, 2009:219). Despite a lack of evidence on this phenomenon, The World Bank Poverty Assessments review found that many developing countries acknowledge that poverty has a strong relationship with disability (Braithwaite and Mont, 2009). For example The World Bank estimates that about 20 percent of those who are living on or below poverty line in developing countries are disabled people (Levinsohn, 2002). Elwan (1999) suggests that this implies a two-way relationship between poverty and disability as poverty may increase the risk of disability and vice versa (Sen, 2009). Nevertheless, 'longitudinal data sets to establish the causal relation between disability and poverty are seldom available, even in developed countries' (WHO, 2011a: 39). Therefore the vicious circle of poverty-disability phenomenon still lacks empirical research, especially in the context of the Global South.

The analysis of the data presented in this thesis thus provides empirical evidence of this poverty-disability phenomenon. The majority of women interviewed were born to low-income families and lived in poverty during childhood. Although Malaysia is currently recognised as an upper-middle income country (The World Bank Group, 2013), it was previously considered as a lower income country following its independence from Britain in 1957. Within only 57 years Malaysia underwent a rapid economic growth after the declaration of ‘Vision 2020’ in the Sixth Malaysia Plan in 1991. Since then the country experienced prosperous economic development and was able to advance its economy to be recognised as an upper-middle income developing country (Economic Planning Unit, 2011; Nirwan Noh, 2004). Therefore most of the women interviewed were raised during a time when Malaysia was still struggling to develop its economy.

Due to their poverty and rurality factors, many of the participants had little access to modern healthcare and this led to the onset of their impairment and/or intensified their impairment conditions. Lack of access to adequate healthcare was significantly associated with disability, as discussed by many women in Chapter 4. This was closely related to the location factor where both rurality and poverty prevented many women from getting access to state healthcare services that were primarily located in big cities rather than rural areas. Although the general population have reasonable access to the government’s healthcare facilities, rural populations, including states with diverse geography such as Sarawak, Sabah and Pahang, have restricted access to local health services (The NGO Shadow Report Group, 2005). The primary healthcare facilities such as hospitals, local clinics and rehabilitation services are mainly located in highly populous areas instead of villages and rural areas (Kuno, 2007; Amar-Singh, 2008). This study found that those women from a deprived family background, and those who lived far from the cities, met with transportation barriers when seeking medical treatment and rehabilitation services from physicians and rehabilitation therapists. Consequently many of them never had the opportunity to diagnose and treat their syndrome or impairment properly and thus they were left permanently disabled.

Fujiura and Yamaki (2000) for example found that there was a growing relationship between poverty and childhood disability in the United States. They examined data from National Health Interview Survey (1986-1996) and observed that childhood disability prevalence had a significant co-relationship with economic status. There was a rising prevalence of disability among poor children and single-parent households showing a greater risk of disability prevalence. However an analysis conducted by Filmer (2008), based on 14 household surveys from 13 developing countries, suggested that there was no significant difference between poverty and childhood disability prevalence except for two countries: Indonesia and India. Based on the available, albeit limited, data Filmer proposed that:

> The prevalence of disability among 6- to 17-year-old tends to be slightly lower in richer quintiles, but the association is not always monotonic. Moreover, India and Indonesia are the only countries in which the prevalence of disability in the richest quintile is statistically significantly different from that in the poorest quintile. In India, prevalence in the richest quintile is about a third of that in the poorest quintile; in Indonesia it is about half (Filmer, 2008: 148).

Many writers have asserted that poverty and disability have a two-way relationship (Emmet, 2005; Elwan, 1999, Sen, 2009; Nagata, 2007); however the existing findings are limited and not necessarily significant, especially in the Global South (Groce et al., 2011; Braithwaite and Mont, 2009). It means that we have a lack of robust evidence to show that poverty increases the risk of disability. Nonetheless data from my research suggests that poverty is not the sole factor associated with impairment but it is coupled with rurality. As Shakespeare points out; ‘people in rural areas are additionally disadvantaged because services tend to be concentrated in urban areas, and because transportation opportunities are limited’ (Shakespeare, 2012: 274). The findings thus supported that both economic and location factors have a strong causal relationship with impairment/disability.

Whilst the available research in the Global South has yet, at time of writing, to establish the fact that poverty can be a cause of disability amongst children, the claim that disability causes poverty has been significantly recognised (WHO, 2011a; The World Bank Group, 2011; Yeo and Moore, 2003; Filmer, 2008; Jonsson and Wiman, 2001). For example data from household surveys in 13 developing countries found that disabled adults usually lived in poorer households and disability increased the risk of poverty by 10 percent (Filmer, 2008).

Furthermore the survey showed that adults with disabilities had a lower educational attainment:

> People of ages 6–17 with disabilities […] are significantly less likely to start school or to be enrolled at the time of the survey. The order of magnitude of the school participation deficit associated with disability—which is as high as 50 percentage points in 3 of the 13 countries […] The results suggest a worrisome vicious cycle of low schooling attainment and subsequent poverty among people with disabilities in developing countries (Filmer, 2008: 141).

A similar trend was observed in this study that many women either did not attain formal education or dropped out of school because of the structural and attitudinal barriers at school. Consequently they had little prospect of employment and economic activities which subsequently increased their risk to poverty. Disability research in Malaysia argued that disabled children, particularly those with severe physical impairment and coming from rural areas, face significant barriers in accessing formal education (Kuno, 2007; Ong et al., 2002). Also previous studies established that employment rates for Malaysian disabled people are low (Ramakrishnan, 2007; Mubarak, 2006; Faridah, 2003; Jayasooria, 1997) and this may increase the risk of poverty among them. As a result all three factors of poverty, rurality and impairment have a strong relationship that influenced how many of the women interviewed were marginalised from wider economic and social participation in society.

8.4 The influence of gender

There is a well-established body of research in the Global North exploring the link between gender and disability and how they intersect and work with each other (Morris, 1999; Thomas, 1999; Lonsdale, 1990; Fawcett, 2000; Wendell, 1996; Garland-Thomson, 2002). This study found that gender has a vital influence in shaping the women’s experiences of living with impairment and disablement in Malaysia. In most aspects of their lives, the data showed that there were gender specific effects in how the participants negotiated their identities as disabled women.

Malaysian society is constructed through explicit traditional gender roles and gender divisions and women's primary roles are restricted to domestic levels despite increasing numbers of women entering the workforce (Noraini; 1999). Women are perceived as playing important roles at home dealing with family and household works; although many of them are also economically active (Yun, 1984; Chattopadhyay, 1997). In other words women in Malaysia should be able to perform basic functions of a daughter, wife and mother, which involve domestic tasks such as cooking, cleaning and looking after the family (NGO Shadow Report Group, 2005; Aminah Ahmad, 1998). This significantly influenced many women in this study as they felt circumscribed from performing women's roles because of their own impairment, structural barriers at home, or disempowerment attitudes displayed by family members (see Chapter 5). Interestingly they did not feel oppressed due to being subordinated to domestic roles as argued by feminist writers (Ferree, 1990; Markusen, 2005), but rather they felt upset as they were not able or allowed to perform such roles. As such for these women the ability to perform traditional gender roles at a domestic level was important for them and had positive impact on their identity construction.

The findings observed that gender relations had a significant impact on the women's healthcare experiences. As discussed in Chapter 4, a significant number of the research participants reported that they had been sexually abused by their traditional healers/shamans and physicians, who were all men. The data thus revealed that disabled women were subjected to sexual abuse at both healthcare settings – traditional and modern/western medicine. Consequently the women involved had long-term psychological trauma resulting from such incidences and some of them discontinued their medical treatments. The result is consistent with the previous findings elsewhere that found disabled women with physical impairments are subjected to physical and sexual abuse by their healthcare providers (Young et al., 1997; McFarlane et al., 2001). This universal characteristic of the female disabled experience that observes an explicit lack of power exhibited by these women towards their healers/physicians had profound impact on their wellbeing. It not only tainted their psychological wellbeing but also prevented them from getting adequate healthcare assistance. This can be intensified by cultural attitudes which witness that many women in a traditional society such as India, particularly villagers, do not seek healthcare assistance from male practitioners (Thomas and Thomas, 1998). It thus implies that disabled women may be reluctant in seeking assistance from male care-providers (Thomas and Thomas, 1997: The World Bank Group, 2009). Therefore it is important to ensure that healthcare settings have an adequate number of female practitioners.

The data also disclosed that many of the women in the study were subjected to different degrees of abuse by men at various life settings. As discussed above, many participants not only had lack of power and agency against men, i.e. the traditional healers/medical practitioners, but also against their fathers, brothers, partners, and disabled men. The power relations that took place in both public and private settings undermined the women's agency as individuals and consequently profoundly affected their wellbeing. For example several women felt constrained by the control of their fathers and brothers from voicing their opinions and wishes. Likewise many other women felt oppressed by being exploited and abused financially, physically and psycho-emotionally by their partners. Not only that but a woman revealed that she was abused verbally, and threatened physically, by male disabled activists for being actively involved in disability activism.

Chapter 1 discussed how Malaysian women are subjected to violence and abuse by men; especially their partners and family members (Rashidah et al.,, 1995; Ministry of Women, Family and Community Development, 2004). Females also remained in second position after males (Noraini, 1999) and men were perceived as 'protectors' of women in Malaysia (Rohana, 1997). It has been argued that globally, disabled women experience a higher degree of social oppression and domestic abuse than non-disabled women (Mays, 2006; Ghai, 2003; UNDP, 1995; United Nations Enable, 2012; Thiara et al., 2012) because they are susceptible to physical, social and economic dependency (Dreiedger, 1996). Therefore it appears that disabled women in Malaysia not only have less power than men, because of their gender position, but their disability also adds another 'disadvantage' making them more 'vulnerable' to violence and abuse by males.

Although the general population in Malaysia reveals that women are increasingly achieving high education as compared to men (Department of Statistics Malaysia, 2011), gender disparities still exist in educational settings. The Malaysian educational system and training are subjected to strong traditional gender stereotyping and influenced by perceptions within society. For example many females declined the opportunity to study subjects outside their gender stereotypes, such as sciences, technology and engineering, despite these careers offering higher payment (Aminah, 1998). Moreover the training programmes for women are designed to fulfil domestic roles such as food processing, tailoring and handicrafts rather than productive roles (Aminah, 1998). Likewise the data shows that the vocational training for disabled people provided by the state and NGOs was limited and gender-based. Despite the significant numbers of women who underwent vocational training for disabled people, the majority of them were assigned to 'feminine' courses such as tailoring. This is often found in other Global South countries such as in Nepal, where disabled women are subjected to gender inequality in terms of training:

> There was also the gender division in the training provided by organizations of and for people with disabilities. Women were found knitting, weaving and tailoring whereas men having computer training, teacher training, electrical training and journalism courses. All of these training courses in which men were involved have a high demand in jobs and receive good salaries. [...] It shows that women were not given any choice in terms of training. They would certainly have better earning potential from computer training or electronic training than from tailoring (Dhungana, 2006: 141)

However in the Malaysian context, the participants were not only restricted from wider career options due to their gender position, they were also subjected to structural barriers at the workplace after completing their training in tailoring. Most of tailoring shops in Malaysia are located on the upper floors and are not accessible to people with mobility impairment; especially wheelchair users. It thus suggests that there was an explicit interaction between gender and disablism that restricted these women's potential and prevented them from equal participation in economic activities.

8.5 The role of family, culture and religion

Despite an increasingly international outlook, Malaysian society still preserves many traditional values (Kennedy, 2002) and an emphasis on the importance of family (Noraini, 1999; Joseph, 2000; Chattopadhyay, 1997). These can be clearly seen in the study in that family played an important role for the majority of participants, as well as culture and religion. The data demonstrated how the women interviewed constructed and negotiated their identities through a dynamic interplay between family, culture and religion. It also provides notions of both homogeneity and difference within and between the three ethnic groups in Malaysia – Malay, Chinese and Indian. The intersection of family, culture and religion is therefore important in the understanding of the female disabled experience in the Global South.

The lack of social care protection from the state, and the collective nature of Malaysian society which is 'sociocentric' and places emphasis on the family bond, have all reinforced a strong dependency on family. As a result family had strong influence in the lives of most participants, across different ethnic groups. While this is a universal experience for the majority of women, some of them felt restricted by the 'powerful' role family had on them when they were negotiating their identities as both individuals and women. Chapter 5 outlined how some women were inhibited from exercising their agency as independent social actors within their families. Chapter 6 also unveiled the women's dilemmas in pursuing their relationships as a result of the repression from their families and their prospective partners' families. These were not singularly related to the notion of family but intersected with culture and religion. The family, culture and religion collided together and played pivotal roles in shaping the women's disability experience.

Chapter 4 discussed how many of the participants, and their families, had a strong belief in traditional medicine. This cultural representation of healing through traditional methods was widespread amongst the participants regardless of ethnic groups and religions. It was closely linked to the notion of how disabled people are perceived within Malaysian society. As argued in Chapter 7 many of the women interviewed were stigmatised and were stereotyped in all of life's settings. Through their daily encounters with others these women were constantly labelled with negative attributes of disabled people. They were associated with 'spoiled identity' (Goffman, 1968) that 'discredited' them as 'different', 'weak', 'dependent', and 'pitiful'. Such negative cultural representations of disabled people continuously reminded these women that they were 'disabled' and not 'normal'. Therefore their impairment had to be eliminated and treated to make them 'normal'. As often observed amongst parents in the Global North (McLaughlin, 2012), many parents in this study also sought medical diagnosis and treatment for their children and traditional medicine (including spiritual/religious treatment) became the most available and acceptable option after modern medicine in Malaysia (Kamil and Teng, 2002; Kamil and Khoo, 2006). This significantly brought psycho-emotional fatigue to many of the women as they were constantly reminded that they were not 'normal' and had to be treated through traditional medicine (for example, see 7.3.1). The strong influence of family, culture and religion towards 'normalizing' the impairment may have caused these women to experience psycho-emotional disablism, possibly preventing a positive aspect of their identity construction as disabled women.

The strong influence of family, culture and religion can also be seen in romantic relationships. It was interesting to note that many of the women interviewed were subjected to strong control from their family or their prospective partner's family in pursuing their relationship (see Chapter 6). This however was not only about family but also culture and religion. The dynamic intersection of family, culture and religion can be observed amongst the Malay-Muslim women in their relationship experiences. For example all Malay-Muslim women adhered to their parental wishes or their prospective partner's family's control in pursuing a marriage plan although it was against their own desires. They would not disobey their families' command due to their strong obedience to Islamic doctrines. As Haque and Khairol argue:

> Within the Malay population, there are also cultural differences from state to state [in Malaysia] but the overall Malay culture is overshadowed by a strong influence of religion (Haque and Khairol, 2002: 277-278).

On the other hand religion was not as prominent a feature for Chinese and Indian participants in this regard (Joseph, 2000). The majority of non-Malay-Muslim participants still proceeded with their relationship or marriage plan despite strong objection from their families or their prospective partners' families. However, none of the participants in all three ethnic groups or religions had children outside marriage due to sociocultural constraints against such practices in Malaysia (Ng et al., 2006; Abdul Aziz, 2001).

Although there were significant differences in the role of religion amongst the participants in terms of familial relationship and personal relationships, the majority of them incorporated religion into their disability identity. Almost all participants used religion to help them adjust to their impairment and to construct (new) meaning in their lives. Disability is thus thoroughly immersed in the belief system of religion (Hutchinson, 2006; Grech, 2012). Whilst many of the women felt ‘devalued’ and ‘differentiated’ in constructing their narratives as individuals with impairment, religion assisted them in coping with such daily oppressive encounters with others (Johnstone, Glass and Oliver, 2007). As Malaysia is a traditional and religious society (Kamal Hassan, 2005) religion serves as a key aspect of identity for the majority of people; especially Malay-Muslim. The strong construction of religious identity within one’s self was reinforced by the family; as many of the women related. Grech argues:

> Belief can also become a critical source of resilience and resistance (even psychological) for disabled people and their families or may compensate for the paucity of other resources such as medical support (to which the poor, particularly in the majority world often have scarce access) (Grech, 2012: 65).

It is therefore important in the understanding of disability experience in the Global South to examine how religion, culture and family intersected and played crucial roles in constructing the disabled women’s narratives. Hence the disability and gender experiences in Malaysia are complex and involve different factors at the levels of individual, the familial and the structural.

8.6 Implications for theory, policy and practice

The previous sections have examined how socioeconomic conditions, geography, impairment, gender, family, culture and religion played vital roles in shaping Malaysian disabled women’s lives. This section highlights some important implications this research raises for policy and practice of disability theory in Malaysia.

8.6.1 Theoretical implications

As discussed the findings indicate that there were complex intersections of gender, socioeconomics, geography, impairment, structural and attitudinal barriers, family, culture and religion in the women's narratives of living with disability in Malaysia. The women's lived experiences were dynamic and reflexive in the sense that they always involved a complex interaction between individual aspects and contextual factors. Therefore the feminist and critical realist approaches, as outlined in Chapter 2 and 3, are seen as providing the most promising insight into the understanding of Malaysian disabled women's lives.

Whilst the feminist approaches may be useful in theorising the gender and disability experiences in Malaysia, it may be restricted by the socio-historical context of the country. As Rohana stresses:

> Feminism is seen in Malaysia as a western concept, and women's demands need to be couched in terms of respect towards the state, family, and religion. Many struggles here are feminist, but not labelled as such [...] Many Malaysian women do not like to be called feminists because feminism has been misconstrued by most Malaysians as a concept and practice imported from the west, particularly by western white women, and is seen as not applicable to local conditions. Neither are women's oppressions ever acknowledged here, and even if acknowledgement did exist, their "oppression" is of a different nature. Women struggle here against all forms of economic and social inequalities, and all forms of violence against them. These are, in fact, feminist struggles, yet they have been named women's struggles for reforms in these spheres (Rohana, 1999: 417)

Recognising the socio-historical context of Malaysian society, the mainstream feminist approaches may be difficult to apply in a local framework. As Ng et al. argue:

> The feminist theories [...] while useful as a start, have not dealt with multicultural contexts or addressed the problems faced by many countries in the South. In multi-ethnic Malaysia, situated within the belly of a globalizing economy and driven by an authoritarian state, the

> women's movement has had to carve a niche for itself to prove its relevance [...] (Ng et al., 2006: 9).

Therefore there is a need to undertake an alternative framework of feminist research which is culturally sensitive, like for example Islamic feminism (see, for example, Yamani, 1996; Fernea, 1998; Naseef, 2007). Owing to the fact that Malaysia is an Islamic state and the majority of people are Muslim, Islamic feminism is seen as more appealing in the local context. Although Malaysian women exist in a multi-ethnic and multi-religious society, the Islamic teachings which are based on the concept of equality for all human beings are seen as applicable to all. Both the primary sources of Islam: the Quran and the Hadith[20] recognise the status of women and people with impairment. In Islam the position of women is equal to men (Engineer, 2004; Al-Hakim, 2005; Naseef, 2007) as Allah (God) says in the Quran that He does not differentiate human being based on gender or ethnic group but rather He looks for their righteous deeds:

> O mankind, indeed We have created you from male and female and made you peoples and tribes that you may know one another. Indeed, the most noble of you in the sight of Allah is the most righteous of you. Indeed, Allah is Knowing and Acquainted (Quran Al-Hujurat: 13).

More importantly God highly values the status of women in Islam as evinced by one whole chapter in the Quran being dedicated to women. The fourth chapter in the Quran is named as *The Women* (An-Nisa) and it makes numerous references to women all through the chapter. Islam also acknowledges the importance of role played by women by looking on them as role models. The exemplary women in Islam were often mentioned both in the Quran and the Hadith for their great contribution to people and religion (Al-Hakim, 2005).

Although in some Muslim societies women are culturally subjected to significant gender inequalities (see, for example, Moghadam, 1991; Moghissi, 2005; Lorber, 2010), the basic doctrines of Islam are indeed against such practices. One should be able to differentiate between cultural practices and religious doctrines. As Naseef argues:

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[20] Hadith is believed to be the words and deeds of the Prophet Muhammad (peace be upon him)

> Islam is a feminist (humanist) religion because the Qur'an's goal is to ensure happiness and fulfilment for women (and men), and advance their holistic welfare. Perhaps on a more basic level, the Qur'an is feminist because it shares many of the same goals for women as they have for themselves (Naseef, 2007: 1).

Islam recognises that women enjoy the same status and dignity as men especially in their rights for social and legal protection, as well as regarding sexuality, marriage and family life (Al-Hakim, 2005; Naseef, 2007; Engineer, 2004). Islamic feminism therefore works to challenge the strong traditional patriarchal practices in society which discriminate women and it believes in gender equity (Samiuddin and Khanam, 2002; Naseef, 2007).

Likewise Islam has a positive attitude towards people with impairment. Islam views impairment from a human rights perspective and emphasises the concept of equality for all human beings (Ali, 2008). The Prophet Muhammad (peace be upon him) says:

> Verily, God does not look at your bodies or your appearances, but looks into your hearts (Muslim, 2564).

The Prophet Muhammad (peace be upon him) also sets many good examples through his generous treatment of those with impairment during his time. Also the Islamic jurisprudence provides a comprehensive guidance for many aspects pertaining to people with impairment, including issues of human dignity, employability, physical and spiritual medicine, and financial assistance, as well as marriage for disabled people (see, for example, Mohammed Ghaly, 2010). Indeed Islam acknowledges the equal status of disabled people and values their role, as well as their contribution in society.

As discussed above, Islam has positive perception of both women and disabled people and it emphasises justice towards them. Therefore keeping with the socio-historical context of the country, Islamic feminism may offer a useful framework for research into disabled women in Malaysia.

8.6.2 Redistribution and recognition

This study provides empirical evidence of pervasive social injustice towards disabled women in Malaysia. As the findings reveal, the majority of participants encountered two types of social injustice: socioeconomic injustice and cultural injustice. In challenging these notions of injustice towards Malaysian disabled women the works of Nancy Fraser (1995; 2000; 2003), which examine the politics of redistribution and the politics of recognition, will be employed.

Nancy Fraser (1995; 2003) has argued that the discourse of social justice is increasingly divided between claims for redistribution and claims for recognition. This, according to her, is rather misleading as she contends:

> […] I assume that justice today requires *both* redistribution *and* recognition. And I propose to examine the relation between them. […] how to conceptualise cultural recognition and social equality in forms that support rather than undermine one another. […] It also means theorizing the ways in which economic disadvantage and cultural disrespect are currently entwined with and support one another (Fraser, 1995: 69, emphasis in original).

Acknowledging the disability phenomenon in Malaysia which stems from both socioeconomic and cultural factors, this particularly true as Anita Ghai asserts:

> While disability advocates in the developed world have progressed from issues of service delivery and rehabilitation to an engagement with the multiple nuances/meanings of disabled existence, the developing world continues to agonise over securing the very basic elements that disabled people need to survive (Ghai, 2009: 283)

As discussed, poverty was widespread among the participants in this study and was closely linked to rurality factor and significantly leading in turn to negative impairment/disability outcomes. Therefore both the politics of redistribution and the politics of recognition are vital to disabled women in Malaysia. The first step to improve the wellbeing of disabled women (people) is through the paradigm of redistributive justice (Fraser, 1995; 2003). The findings confirmed that Malaysian healthcare system in rural areas is very limited (Kuno, 2007) and early disability assessment as well as intervention are inadequate amongst children (Amar-Singh, 2008). Consequently poor and rural children have an increased risk of acquiring poor impairment and disability outcomes. The

Malaysian government should improve its healthcare system in terms of early disability assessment, intervention and rehabilitation for both rural and urban people. The Ministry of Women, Family and Community Development (MWFCD) and the Ministry of Health (MOH), which provide primary services for disabled people, need to collaborate and work closely together. There is a lack of integrative collaboration between state agencies in dealing with issues of disabled people (Wan Arnidawati, 2013). For example the MOH should refer their patients to MWFCD for further assistance and *vice versa*. This could reduce the risk of impairment, poverty and disadvantage amongst disabled children and women.

The evidence in this study also established the fact that disability support for disabled children and their families was at best very little and often absent. Many of the participants who had, or acquired, their impairment from an early age reported that they had limited access to family life, education, training and subsequently employment due to poverty and geographical factors as well as driven by poor social care protection and disability support from the state. The poor and inaccessible housing caused some women to spend their childhood in welfare homes and denied their right to a family life. Whilst the family was vital to many women, including the traditional caring roles primarily provided by the family, little support was given by the state to families with disabled children. The effects were even greater for mothers and female family members who had to sacrifice their time, energy, and sometimes educational and employment prospects, to look after their disabled daughters/siblings.

The state multi-agencies should work together in supporting the ability for disabled children to live within their family and to cater for their basic needs in terms of financial resources; such as accessible housing, mobility and rehabilitation aids, as well as psycho-emotional support for carers. This could be done through active collaboration between the Ministry of Urban Wellbeing, Housing and Local Government (MUWHLG), MWFCD and MOH. As a result the familial burdens could be reduced by meeting the needs of disabled children without denying their right to a family life. The state agencies could also conduct outreach programs for those living in poverty and far from cities so that they would not be excluded from receiving disability support from the state. The findings demonstrated that the majority of support and facilities granted to disabled people are centred in big cities instead of in rural communities. Many participants lacked information and resources from the Department of Social Welfare (DSW) about social care protection and as such they were marginalised from those schemes. Therefore the disability welfare should be made available and accessible to all people from diverse socioeconomic and geographical backgrounds.

Lack of integration between the DSW and the Ministry of Education (MOE) was also apparent as many of the participants encountered significant barriers in terms of their physical environment at school (Ong et al., 2002) and the disabling attitudes of school authorities and students. It was argued that students with severe physical impairment were often excluded from school because the responsibility to look after them lies within the scope of the DSW and not the MOE (Kuno, 2007). Therefore the DSW and MOE should work together to support the needs of students with physical impairments at school as well as at higher learning institutions (Hasnah et al., 2009). The restricted educational opportunities subsequently led to long-term life outcomes such as limited employment and career prospects. This consequently exposed many of the women interviewed to greater risk of poverty and socioeconomic disadvantage.

Gender inequality was also observed in terms of training provided by the state and the NGOs. Disabled women were assigned to crafts, or feminine courses like tailoring; while men were enrolled on mechanical courses, such as repairing cars, televisions, and radios. Such gender bias in vocational training for disabled women may have impeded their full potential for employment or career development and this is significantly related to the strong traditional gender roles in Malaysia as discussed above. Therefore gender equality should be addressed within the educational and training system for disabled people. The DSW and NGOs should offer a variety of training programmes for disabled women to encourage wider career prospects. This could prevent disabled women from being subjected to ‘multiple discrimination’ in training and employment. As a result wider opportunities in training for disabled women would significantly increase the likelihood of financial independence.

Indeed equal distribution alone is insufficient, yet recognition parity is congruently important for disabled women as Fraser argues:

> Within social movements such as feminism, for example, activist tendencies that look to redistribution as the remedy for male domination are increasingly dissociated from tendencies that look instead to recognition of gender difference [...] These, I maintain, are false antitheses. It is my general thesis that justice *both* redistribution *and* recognition. Neither alone is sufficient (Fraser, 2003: 8-9, emphasis in original)

Therefore the second vital step to address the social injustice towards disabled women in Malaysia is through the politics of recognition. Malaysian disabled women have to struggle for recognition; both as individuals with impairment and as disabled women. The political struggle for social recognition and equality before law has been rooted in the long-term struggles of disabled people in Malaysia since the colonial period (see Chapter 1). Although in recent years the Malaysian government proclaimed its commitment to shift its paradigm from a charity approach to a rights-based approach with the ratification to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008, and subsequently introduced the Persons with Disabilities Act (PWDA 2008) in the same year, disabled people still experience significant stigma, oppression and discrimination in society as this thesis documents.

It is argued that the PWDA 2008 failed to put disabled people on the mainstream agenda and proved politically incapable of recognising the rights of disabled people due to the absence of a penalty for non-compliance (Malaysian Bar Council, 2009; Jayasooria, 2000). Therefore it is only through equality law recognising the rights of disabled people that Malaysian society will grant them social justice. There is an urgent need to establish the Disability Discrimination Act in Malaysia which should cover all aspects of life in order to replace the PWDA 2008. The implementation of this discrimination act will not only recognise the rights of disabled people and eliminate the societal oppression and discrimination towards them; it will also empower them to have self-respect within society. It will also educate society that disabled people are not ‘different’, ‘weak’, ‘dependent’ and ‘pitiful’ but that they are equal before the law. This equality law is envisaged to bring significant changes to the physical environment for people with physical impairments and concurrently to societal attitude:

> Changing the physical environment is indeed essential to improved access to public space for disabled people but so also is changing the social environment, and in particular, changing social attitudes and behaviour towards disabled people. […] There may of course be a link between the limitations imposed by the physical and social environment—thus a physical environment which enables the presence of disabled people in public space may stimulate positive social attitudes towards people with bodily impairments and more positive attitudes should encourage more positive physical planning (Butler and Bowlby, 1997: 411-412)

Consequently the implementation of equality law in Malaysia may change the cultural conception of disability from a ‘charity approach’ to a ‘rights-based approach’ and as such it will increase the societal awareness of the importance of equal opportunities for social and economic participation for disabled people in the country and grant them justice.

Crucially disabled people in Malaysia also need a better cultural representation as ‘recognition is rooted in social patterns of representation, interpretation and communication […]’ (Danermark and Gellerstedt, 2004: 344). Riddell and Watson argue:

> In contrast with earlier writing which focused on disability as social and economic oppression, disabled people have recently come to see cultural revaluation as central to their political struggle. Writers such as Anne Karpf (1998), Tom Shakespeare (1994), David Hevey (1992), Martin Norden (1994) and Lois Keith (2000) have sought to show how images of disabled people are used to in the media and in literature. They point to the media fondness for cure stories; the role of charity appeals; the invisibility of disabled people on television; the stereotyped portrayal of disabled characters in screen drama; the under-employment of disabled people in broadcasting; the representation of disabled people as flawed or damaged (Riddell and Watson, 2003: 2)

In view of that Malaysian mass media should integrate disabled people into their mainstream agendas to empower them, as well as to encourage positive representation of disabled people in society. Nevertheless Fraser proposes that we should avoid an identity model of recognition which assumes that disabled people have a universal shared identity. Instead the politics of recognition should emphasise a social status perspective that focuses on participation parity (Fraser, 2000). This is particularly relevant to disabled women in Malaysia with diverse sociocultural backgrounds and identities. The Malaysian disabled women in this study constantly fought to prove to their family and people surrounding them that they were capable of becoming active social agents in society. They challenged the social stigma, prejudice and discrimination that people displayed towards them in many aspects of their lives, in both the public and private spheres, and both as disabled women and individuals. This is closely linked to gender gap in Malaysia that strongly perceived women as ‘weak’ and ‘dependent’ on men (Rohana, 1997) as well as being assigned to domestic roles and stereotypes (NGO Shadow Report Group, 2005; Aminah, 1998). As such there was little room for these women to exercise their agency at the levels of personal and political. Therefore Malaysian disabled women need better representation in the mainstream media to recognise their rights as individuals and women with impairments.

The mass media should foster a positive image of disabled women with different roles and abilities also including the portrayal of disabled women in traditional roles as wives and mothers (Fine and Asch, 1988 cited in Barnes and Mercer, 2010: 194). Whilst it may not be popular amongst many feminists to encourage such stereotypical gender roles, disabled women want the media to display a variety of images of disabled women; including those with domestic roles as wives and mothers (Barnes and Mercer, 2010) to counter the societal misconception of them. Such media representation is important for disabled women as many participants were culturally denied their rights for a family life due to lack of societal understanding regarding their abilities to become wives and mothers. Therefore constructive media representation of disabled women playing different roles in society may encourage positive societal attitudes towards them from their own families, friends, employers, partners, prospective partner’s family and members of the public.

In addition the MOE could play an effective role in promoting disabled people’s rights to the rest of population. The state educational system should incorporate disability issues in its curriculum to promote public awareness; especially amongst children. If people are exposed to disability related issues from an early age, they may have a better understanding of, and more positive attitudes towards, disabled people. In the long term it is expected that the public’s perception towards disabled people may improve and eventually produce a non-disabling and equal society.

The representation of disabled women at the political level is very limited including through disability activism. The Malaysian political system is largely dominated by males (NGO Shadow Report Group, 2005; Wan Azizah, 2002; Women's Aid Organisation, 2012) and this was reiterated by a woman in this study who was subjected to physical and verbal threats from male disabled activists. This could block disabled women from equal participation in disability politics. Also the local political climate can impose significant political restrictions on women's activists (NGO Shadow Group, 2005; Women's Aid Organisation, 2012) and those working as civil servants (CUEPACS, 2008), and may impede disabled women from effective political participation (see Chapter 1 and 7). Without equal participation in disability politics, issues involving disabled women may not be successfully taken into the state's consideration.

Therefore disabled women should be empowered to take part in disability activism and they should be given participation parity in the political arena. For example Frohmader and Meekosha (2012) highlight how the Women with Disabilities Australia (WWDA) organisation successfully gained political recognition and representation in the country across the private and public spheres. However disabled women's activists/movements in Malaysia may face significant barriers in putting forward their agendas as a collective effort. Malaysian disabled women are a non-homogenous group with multiple identities, interests and beliefs. Hence in order to ensure effective political representation of Malaysia disabled women, the disabled women's activists/organisations should incorporate diverse sociocultural backgrounds and interests within its members.

Nonetheless the Malaysian parliament recently elected a new female disabled senator as a second senator after the demise of the first disabled male senator (Haikal, 2013; The Star Online, 2013). Whilst this is a positive effort in recognising female disabled activists at the state level, Malaysia needs greater representation of disabled women in all aspects of life, including higher decision-making positions, and at both private and public sectors, to fully integrate them into mainstream society. However this can only be achieved if in the first place disabled children and women are given equal opportunity in education, employment, family life and public affairs. Taken all this into consideration indicates the equality law (Disability Discrimination Act) is crucially important in granting Malaysian disabled women justice and dignity in a patriarchal and disabling society.

8.6.3 Exploitation, violence and abuse

The disabled women in this study were not only subjected to stigma, prejudice and discrimination in all aspects of their life, but also suffered from exploitation, violence and abuse. This alarming phenomenon is consistent with the findings across the globe (Mays, 2006; Ghai, 2003; UNDP, 1995; United Nations Enable, 2012; WHO, 2011a). In general Malaysian women are subjected to higher risk of violence especially at home (Rashidah et al., 1995; Ministry of Women, Family and Community Development, 2007; Ng et al., 2006; Aminah, 1998). This effect could be greater for Malaysian disabled women as a result of both their gender and disability (NGO Shadow Report Group, 2005). The UNCRPD addresses about freedom from exploitation, violence and abuse against disabled people in the Article 16 (United Nations Enable, 2014). Therefore in agreement with the Article 16 of the UNCRPD (United Nations Enable, 2014), this issue should be addressed effectively to ensure that Malaysian disabled women are protected against any forms of exploitation, violence or abuse in various life settings. The first and foremost issue to address is sexual abuse in healthcare settings – in both the traditional and the modern healthcare practice. This thesis has documented that significant numbers of women were subjected to sexual exploitation either by their traditional healers or physicians. McFarlane et al. (2001) and Young et al. (1997: 43) argue that disabled women with physical impairments are at higher risk of being abused sexually and physically by their healthcare providers. However little is known about sexual abuse in the traditional medical environment and the findings established that sexual abuse against disabled women could occur in both settings – modern and traditional. The state should strongly address this issue by instructing the MOH to protect disabled women from being sexually exploited by their physicians or attendants. The state should take all appropriate measures to educate disabled children and women, as well as their families, about different scenarios which may occur during physical examinations and what may be considered as unethical practice in modern medicine. The imbalance of power between healthcare providers and patients should be reduced and at the same time disabled children and women should be empowered to report any malpractice done by their healthcare providers. In so doing disabled children and women could hopefully be protected from such disturbing occurrences that may act to impede their wellbeing.

Equally important is that this issue should also be addressed in the context of traditional medicine. Whilst traditional medicine is culturally acceptable amongst many Malaysians, and across different ethnic groups and religions, parents of disabled children should be made aware of potential dangers to protect their children from being sexually exploited. For example disabled children and women should not be allowed to attend appointments with traditional healers alone and they should be accompanied by at least one family member or friend at all times. They should also be encouraged to report such incidences to the state or local authorities even if it involves someone known to their family or a respected figure in their hometown.

Secondly, disabled women should be protected from violence and abuse at home from their own family members and partners. The findings are consistent with the current trends in Malaysia that observed women generally are highly exposed to domestic violence by their partners (Rashidah et al., 1995) and many of them did not report their case (Ministry of Women, Family and Community Development, 2004). Whilst the state has enforced the Domestic Violence Act in 1994, violence against women continues to rise despite significant efforts by social activists over two decades to eradicate this issue (Ng et al., 2006). Therefore women with impairments are foreseen to be at greater risk of domestic violence than non-disabled women. The MWFCD should pay more attention to this when addressing the issue of violence against women at the state level to recognise that disabled women could be amongst the most ‘vulnerable’ and ‘disadvantaged’ group.

Protection services should be made easily accessible for those in need, including legal advice and protection as well as physical and psycho-emotional supports such as providing shelter, counselling and psychotherapy during and after the traumatic experience. The social activists and women’s activists should also include Malaysian disabled women as one of their focus groups when dealing with domestic abuse so that they will not be marginalised from the mainstream women’s agenda. The MOE should play an educative role to the major population by promoting gender equality and protection against violence amongst schoolchildren. Traditional gender norms and stereotypes should be addressed within the schools' syllabuses. As a result in a long run this may significantly prevent gender inequality and power imbalance amongst the population.

Finally the prevailing financial exploitation experienced by many of the women interviewed should be eradicated. There were two scenarios that observed disabled women who were subjected to financial exploitation – in a romantic relationship and in the context of traditional medicine. The former may prove difficult to overcome as it involves personal feelings and aspirations of being a woman as well as relating to the negative cultural representation of disabled people in Malaysia. These women wanted to experience love and getting married yet their aspirations were exploited by men who took them for granted because of their disability and gender position. While this may sound straightforward the women involved might not perceive it as a simple issue for them to escape from such abusive relationships. Therefore the state and disability activists should address this issue and empower disabled women to protect them from such of exploitation. Disabled women should be empowered about their rights and right to dignity as women and individuals in pursuing their relationship with their partners. At the cultural level all parties, including the state, disability activists and mass media, should cultivate positive images of disabled women as daughters, partners, wives and mothers, as well as students, employers and public members and also as leaders in Malaysian society. Such a dynamic representation of disabled women may empower them to exercise their power and agency as well as nurturing positive societal attitudes towards them.

In the second scenario, which involved financial exploitation perpetrated by the traditional healers, the state should play an active role in educating the parents of female disabled children, and disabled women, of the risk of such exploitation. Although it may be difficult to disregard the importance of traditional medicine amongst the majority of Malaysians seeking a cure, appropriate measures could be taken by addressing this issue in a manner similar to that previously discussed with the sexual abuse phenomenon. In so doing disabled women and children may be protected from becoming victims of such financial exploitation.

8.7 Concluding remarks

This chapter so far has recapped the major themes which emerged from the research findings, as well as discussing some suggestions for the theoretical analysis and policy implications. The thesis suggested that an understanding of disabled women's lives in the Global South requires complex levels of analysis incorporating different features of the local cultures and circumstances. Therefore it is proposed that an alternative framework of feminist research i.e. Islamic feminism is useful in providing a more culturally sensitive approach of disability and gender research in Malaysia. This final section therefore discusses some limitations of the study and its implications for future research as well as a self-reflection for the study.

As indicated earlier there has been very little research on disabled women in Malaysia despite significant numbers of disability research studies conducted in a local context. This implies that empirical evidence of the lived experiences of Malaysian disabled women is very limited and thus comparisons to the research findings could not be established. While this creates some drawbacks in finding research literature, at the same time it becomes a major strength of this study. The thesis does not only explore the narratives of the women interviewed but it also offers a novel understanding of disability and gender experiences in Malaysia as well as in the Global South. This opens up a huge loophole on disability research in Malaysia and thus suggests a wider prospect for future research involving Malaysian disabled women.

Another research limitation is the language barrier. Chapter 3 discussed some difficulties in recruiting participants from Chinese ethnicity due to my inability to speak Chinese. This showed that language barriers can be a hindrance in getting wider participation of potential participants from different ethnic groups. It is therefore important to employ a researcher or assistant who is an insider or native speaker to a particular ethnic group to overcome such limitation of cross-language dilemma in future research. Besides, working on cross-language research involves translation issues that may limit the analysis and finding outcomes (see 3.4.3). Whilst many of the 'exact words' used during the interviews were 'lost' in the translation, all appropriate measures have been conscientiously undertaken to address this issue so that the possible impact could be reduced.

The research also focuses on women with mobility impairment and does not involve women from other categories of impairment. In view of that the findings may not be applicable to those with other types of impairment. Nevertheless many issues unveiled in this research are linked to the general findings found in other disability research in Malaysia. Accordingly prospective research may include women from different category or level of impairment to gain broader understanding of disability and gender experiences in Malaysia. Likewise this study does not include participation from the family of the women interviewed and therefore their views may be equally as important as those of the research participant and could potentially be discovered in the future research.

To engage in self-reflection it is necessary to state that this study is very close to my heart as a Malaysian disabled woman. Being a Malaysian woman with physical (mobility) impairment, I have undergone significant social injustice in a similar manner to the majority of participants described. Although we had some differences, our life ambitions were almost the same – to lead an independent life with courage and dignity. As indicated in Chapter 3, I nearly went into a state of depression when completing the participants' interviews and transcriptions. Imagining how their life was so 'tragic' made me felt upset and guilty. When they were saying that they had to stop schooling due to disabling barriers and attitudes at school, I felt so blessed that I managed to overcome those challenges with powerful support from my family. When some women disclosed that they had been abused sexually, physically and psycho-emotionally by men, I was devastated as I never imagined experiencing such traumatic life episodes. Yet I was able to surmount the upheaval of sharing this intense psycho-emotional journey with them and eventually it turned to be my life's endeavour to protect them from such negative outcomes.

As a Muslim woman living in a traditional patriarchal and disabling society, my religious identity grew stronger from combating all difficulties that I met with in my life. As described by many of the participants, the only possible way to cope with the daily societal oppressive attitudes towards us was through religious identity. Although Islam places emphasis on the concept of equality and justice for all, and so do other religions with exception of some concepts in Hinduism, many people were unable to follow such religious principles and acted in opposite way. Therefore it could be said that it was not religion at fault but the negative cultural conception of disability and women in Malaysia that should be eliminated.

Often my ‘stubbornness’ in resisting all stigma and discrimination in society proved to be the best recipe for success. While I had autonomy in pursuing my life aspirations, many of the women I interviewed had very little opportunities for their liberation. However life was not as simple as it seemed to be for many of them. I soon realised that the social oppression was not the only barrier stopping many of the women from being equally included in society. Yet individual constraints such as the nature of their impairment, and the hierarchy of impairment, as well as the effect of gender and the powerful influence family, culture and religion had on them, proved to be equally important. I was aware that in order to put Malaysian disabled women into the mainstream agenda I should be able to interrogate the different contexts, meanings and experiences as described by the research participants. What is paramount is the presentation of their lived experiences from their own perspectives – they were the voices and I was the pen. With this in mind I hope that this thesis grants them justice for their voices to be heard at local, national and international levels. Hence the completion of this research would allow me to work closely with disabled women in Malaysia, both as a disabled woman’s writer as well as an advocate for their rights – a life venture that I can wait no longer to commence.

In conclusion this study contributes a new understanding of the lived experiences of Malaysian disabled women. It provides a valuable insight for disability researchers, policy makers, practitioners, disability activists and women’s activists in Malaysia, as well as in the Global South and the Global North.

Appendix A: Participant information sheets

A Study on the Experiences of Physically Disabled Women in Malaysia

Salam Sejahtera!

You are cordially invited to participate in a research project. Please read and consider the following information about the research and please do not hesitate to ask for clarification if anything is not clear.

Researcher Information

My name is Aizan Sofia Amin and currently is a PhD student at the University of Glasgow, United Kingdom. I am conducting a PhD research to know about the lived experience of physically disabled women across different ethnic groups in Malaysia. As a Malaysian disabled woman, I myself interested to learn about how disabled women experience their lives. For this purpose, I will be conducting the interviews and carrying out the analysis of the PhD study. My PhD research is being supervised by Professor Nick Watson (Nicholas.Watson@glasgow.ac.uk) and Dr. Charlotte Pearson (Charlotte.Pearson@glasgow.ac.uk) at the University of Glasgow. If you have any questions or concerns, please contact me by phone or by email.

Please take time to read the following information carefully and discuss it with me or anyone else if you would like. Please contact me if there is anything you are unsure about or has not been made clear.

1. Purpose of the research study

The interview portion of the research will take place between November 2011 and March 2012. The research study sets out to gain insight into Malaysian disabled women aged 18-55 and their experiences. It is particularly interested to understand their experiences, thoughts and feelings in their everyday lives. Therefore participation will involve participants giving information about their lives; daily activities, education, employment, family background, relationship and also personal thoughts and feelings in relation to their disability.

I am asking around 30 physically disabled women aged 18-55 to participate in the research. I will interview each person twice who will last as long or as little as you feel comfortable with, or which will last about an hour.

2. Is participation voluntary?

Your participation in the research project is on a voluntary basis and you are able at any time to withdraw from participation without reason.

3. What will taking part involve?

If you decide that you would like to participate in the research project I will contact you to arrange a time for you to be interviewed. You will be essential in deciding where and when the interview will take place. The interviews should not take much more than an hour, but will last as long as you are happy and comfortable.

I will ask some information about your daily activities, education, employment, family background, relationship and also personal thoughts and feelings in relation to your disability. The discussion will be in a friendly nature and you will be expected to share (openly) your experiences, thoughts and feelings about your life.

With your permission, I would like to tape-record the interview. The interview will be taped using a digital audio recorder, unless you are not comfortable with this and would prefer not to be taped. Using an audio recorder will allow me to represent what you have said properly. Only I will have access to the recording and it will be safely kept on a file in a password protected computer. After the research project is finished the recordings will be destroyed. They will not be labelled so you will not be identifiable from the recording.

4. What will happen to your information?

All the information that is gathered throughout the course of the research project will be made confidential. You will be given a pseudonym to make sure that your identity is kept anonymous. Any information about you including your consent form, name, audio recording and so on will be stored securely on either in a locked filing cabinet or a password protected computer.

5. Contact Information

If you have any questions, concerns or queries about the research, please do not hesitate to contact me. You are welcome to raise any concerns or complaints about the research or the way it has been carried out with me, my supervisor or the ethic committee all of whose contact details are listed below. You should feel free to provide any feedback, questions or concerns and are most welcome and invited to do so.

I can be contacted via telephone on or by email.

My primary supervisor can be contacted via telephone on or via email Nicholas.Watson@glasgow.ac.uk

Furthermore you can contact the chair of the ethics committee, College of Social Sciences - Dr Georgina Wardle via email office@lbss.gla.ac.uk

Thank you for taking the time to read this information sheet.

I look forward to hearing from you soon.

With Many Thanks,

Aizan Sofia Amin

Appendix B: Informed consent form

University of Glasgow

Consent Form

A Study on the Experiences of Physically Disabled Women in Malaysia

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I confirm that the interview will be recorded with my consent and that in the transcript and research report a pseudonym or code identifier will be used. The data will be used for the purpose of research only.

4. I agree to take part in this research without any compulsion.

5. I authorize the researcher to use the data generated by this discussion for the purpose of her research.

Name of participant : ....

Signature of participant : .... Date: .... Time: ....

Place : ....

Contact details for the researcher:
Aizan Sofia Amin
Telephone number:

Contact details for the chair of the ethics committee, College of Social Sciences: Convenor - Dr Georgina Wardle
Email: office@lbss.gla.ac.uk

Appendix C: First interview guide

Introduction

- Read through information sheet
- Explain ethics
- Gain consent
- Begin interview
- Get interviewee to introduce self to tape

Background

- About self
- Location
- Family
- Ethnicity
- Religion

Impairment/disability and healthcare experiences

- Nature of impairment
- Diagnosis and medical treatments
- Current conditions and health

Education/training experiences

- Academic background?
- Opportunity for education/training?
- Barriers to education/training?

Working experiences

- Working background/experiences?
- Opportunity for employment or self-employment?
- Barriers to employment or self-employment?

Family and peer relationship

- Parents
    - How is your relationship with your parents?
    - How do your parents view/treat/respond to your disability?
    - How do your parents treat you in relation to other siblings?
- Siblings
    - How is your relationship with your siblings?
    - How do your siblings view your disability?
    - How do your siblings treat you in the family?
- Friends

    - Do you have many friends?
    - Opportunity and barriers to form friendship with disabled and non-disabled friends?

Personal relationship

- Relationship/marriage status?
- How do you view a relationship and marriage?
- Opportunity and barriers to form a relationship and marriage?
- Opportunity and barriers to motherhood?

Interview feedback

- Any question to the interviewer?
- How do you feel about being interviewed by the interviewer?
- Any suggestion/recommendation for the interviewer?

*Note: This is a semi-structured interview and it allows for flexibility in the substance and arrangement of the interview questions.

Appendix D: Second interview guide

Current conditions/life changes

- How do you feel right now?
- How is your health/impairment?
- Any changes in your life since the first interview?

Traditional/alternative treatments

- Have you received any traditional/alternative treatments?
- Any positive/negative experiences in relation to that?

Exploitation, violence and abuse

- In any life settings?
- How it affects you physically and psycho-emotionally?
- How do you cope with it?
- How do you feel about it now?

Disability welfare

- Do you receive any financial/equipment/medical aids from the state/any parties?
- How is the attitude of the service providers to you?
- General opinion/suggestions for disability welfare in Malaysia
- Specific opinion/suggestions in relation to yourself and disabled women

Current well-being (feelings and aspirations)

- How do you feel right now?
- What do want to do/have in the future?
- Any suggestion/recommendation for the interviewer

*Note: This is a semi-structured interview and it allows for flexibility in the substance and arrangement of the interview questions.

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