

THE ROAD TO SELF-EMPOWERMENT: MALAYSIAN DISABLED WOMEN EXPERIENCES IN NEGOTIATING SELF WITHIN FAMILY

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ABSTRACT

Family plays a crucial role in the lives of the majority of Malaysians, especially women. As a collective society, Malaysia places emphasis on unity and a sense of belonging to family. This study explores how disabled women in Malaysia experienced care within their familial environment and how they negotiate self within family in their road to self-empowerment. The data were obtained from in-depth interviews with 33 Malaysian women with physical impairment in Peninsular Malaysia. The research findings observed that 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. Whilst the majority of women received positive support from their family, some of them, did not. Some women revealed that their family had a negative attitude towards their impairment; either explicitly or implicitly. In addition, some women felt that they were a burden to the family because of the negative treatment that they received from their family members while some of them felt 'guilty' and a burden to their family because they were supported so much by them. Many of the women interviewed also informed that they were over-protected by their parents which made them unable to be independent both financially and emotionally. This type of care enforced dependency on the family and led these women to experience disempowerment. Therefore, this paper will discuss how these type of familial care and support significantly impacted on the wellbeing of Malaysian disabled women in their road to self-empowerment.

Key words: Self-empowerment, disabled women, family, disempowerment, Malaysia.

INTRODUCTION

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 like Malaysia experience higher numbers of disabled people and thus require specific attention and tailored intervention plans.

It is argued that disability is influenced by cultural variables - it is shaped by how societies perceive disability and impairment (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). 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 developing countries may have different and pessimistic attitudes towards disability when compared to developing world. As such an attempt to change attitudes towards disability among people may become one of main objectives for disability policy in developing countries whereas the question of attitudes towards disability and impairment may no longer be of primary concern in developed nations.

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; 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.

In the case of Malaysia, 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). The only available data on disability prevalence is the number of disabled people who are voluntarily registered with the Department of Social Welfare (DSW). Until January 2017, only 411,482 disabled people are registered with the DSW (Department of Social Welfare, 2017). 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.

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.

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). As a collective society, family plays a crucial role in the lives of the majority of Malaysians, especially women (Aizan et al., 2016). Early life experience in family is important and it can affect the development and child behavioral pattern (Bowlby 1969). Family is a comprehensive structure composed of the interdependent elements that affect overall family function (Shaffer 2002). Children with disabilities for example requires not only affection of their families, but more importantly they need care and protection from facet of physical, emotional and psycho-social support. Disabled people usually have limited capability and more likely to be isolated from their environment. Thus, family plays an important role in supporting disabled people's needs and potential for their survival in society (Kulagina 2003).

Previous researches found that many family members reported experiencing difficulties and complex issues in providing care and support for disabled family members (Santamaria et al. 2012; Cuzzocrea, Larcán & Westh 2013). For example, non-disabled siblings informed that they have difficulty in forming family relationships with their brother or sister with disabilities (Cuzzocrea, Larcán & Costa 2014). Another study found that families of children with disabilities always face psychological, physical and financial issues and at the same time often feel worried about the future of their disabled child (Kilic et al., 2013). Therefore, this study explores how disabled women in Malaysia experienced care within their familial environment and how they negotiate self within family in their road to self-empowerment.

METHODOLOGY

This qualitative 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. The data of this study was collected from in-depth interviews with 33 Malaysian women who had physical (mobility) impairment as a result of spinal cord injury, polio, spinal muscular atrophy, muscular dystrophy, marfan syndrome, systemic lupus erythematosus, traumatic brain injury, gestational diabetes mellitus, osteosarcoma, spina bifida, teratoma, dysmelia, leg amputation and leg injury.

The research participants' age ranged from 21 to 57 years old. They were recruited from three main ethnic groups in Malaysia: 17 Malay, eight Chinese, and eight Indian women. The recruitment of the participants took three different strategies – recruitment via: non-governmental organisations (NGOs) for disabled people (six NGOs for disabled people in Malaysia), disabled friends' networking, and snowballing (Lewis-Beck et al. 2004). The recruitment of the participants took three different strategies – recruitment via: non-governmental organisations (NGOs) for disabled people (six NGOs for disabled people in Malaysia), disabled friends' networking, and snowballing.

This full qualitative research used narrative approach (Creswell, 2007; Jovchelovitch & Bauer 2000) that explores the lived experiences of the research participants. The majority of participants were interviewed twice in 6 months to understand their lives in relation to employment experiences. The time interval between the first and second interview was 3 to 6 months. The in-depth interviews were conducted twice to give space to the research participants to share experiences that are more sensitive in the second interview. They were interviewed in a conducive environment such as at the non-governmental organization premises and the research participants' home. The data gathered from the in-depth interviews were transcribed and then organised in a computer software – QSR NVivo 9 and they were analysed by using thematic analysis (Bazeley 2007; Creswell 2007; Gibbs 2011). The study used qualitative approach and therefore the findings cannot be generalized to a larger population.

RESULTS AND DISCUSSION

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. 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 self-empowerment process. The discussion will revolve around five main themes: the primary care, family conflict, unwanted child, a burden to family and being in(dependent).

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 Deepa¹ 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. Whilst the majority of women received positive support from their family, some of them, did not. The next section will explore how these women negotiated their identity within their family from the varying levels of support they received from them.

Family conflict

The previous sections discussed how culturally in Malaysia the family is expected to provide primary care for the majority of women and the family became the central focus for the majority of women interviewed. 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 earlier, 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.

¹ All the participants' names were referred to using pseudonyms to protect their identity and to ensure anonymity.

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.

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.

A burden to family?

Despite being accepted by her mother, Dilah (as discussed above) 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) 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 disability' (Thomas, 2007; Reeve, 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.

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, 1990: 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 developed nations 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. 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.

CONCLUSION

This study 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, 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 (2007) and Reeve (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.

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. This article outlined how some women were inhibited from exercising their agency as independent social actors within their families.

Therefore, significant effort should be done to empower disabled women in their family and society. 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.

Parents to disabled children should also be exposed to understand the complex needs of their child and develop their potential as an independent human being in the family and society. For example, the Ministry of Women, Family and Community Development could introduce a specific parenting module to train parents with disabled child on how to cater the physical, psycho-social and emotional needs of their disabled child and how to develop their potential within their individual capacity. Such exposure and proper training towards parents with disabled child may help to promote self-empowerment among disabled children and women. As a result, disabled girls and women may develop their own potential and autonomy in their road to self-empowerment that lead to an independent life in their family and community.

This study used a full qualitative research approach and consequently the findings cannot be generalized to a larger population. Another research limitation is that it 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.

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 and the global world.

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