

The Perspective of Social-Medical Disability Model Towards People with Disabilities in the Malaysian Context

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Abstract: In the medical model, disability is perceived as a chronic issue that may involve physical or mental disability which subsequently leads to the inability to work and be actively involved in society. Contrastingly, the social model perceives individuals with disability as minority group that suffers from discrimination, stigma, social alienation, repression, isolation and various social barriers which prohibit them to be well accepted by the society. However, the model that is suitable to be used in the Malaysian context still remain unanswered. This issue is crucial to be investigated because the medical model perspective has been lacking in the Malaysian community towards the disabled. Furthermore, it is also linked to capitalism and meritocracy which have been dominating the world community (McLaughlin and Kenji Kuno). The current study used the grounded theory method to explore and generate a disability concept according to the perspective of social and medical model towards individuals with disability in Malaysia. The grounded theory analysis yields five perspectives in the social-medical model, namely acceptance, independence, equity, accessibility and power to make decision, followed by three sources of social-medical model which include self-awareness towards individuals with disability, society awareness and parents awareness. The grounded theory also includes six barriers of social model, namely inequity, stigma, discrimination, barrier, isolation and ineffectiveness of the law, followed by two strategies involving the idea of getting support and getting knowledge) and finally, the influence of social-medical model (well-being). It is concluded that by determining and producing a new disability model from the existing social model and medical model, it could provide a valuable information especially to the government prior to the implementation of programs or policies.

Key words: Social, medical model of disability, quality of life, people with disabilities, well-being

INTRODUCTION

In the medical model, the main problem faced by individual with disability is the inability to work and be fully involved in the society. This perspective brings many effects towards the life of Persons With Disabilities (PWDs) due to the fact that they are perceived by the medical model as someone with the nature or traits that is generally linked with disability, interdependence as well as social and economic isolation (Scotch, 2000). Hence, many PWDs are unlikely to marry and prefer to live alone, including being less socialise with peers as well as less involved in religious, recreational or group activities (Schur, 2002). The isolation experienced by the PWDs also stems from the difficulties to access the transportation facilities (Louis, 2000) which restricts their mobility thus leading them to isolation.

Apart from that, isolation in education is also one of the main issues included in the policy of disability. This isolation leads to lower level of education among the PWDs (Kruse, 1998) compared to the non-disabled persons. In reference to the social model perspective, although PWDs are given the same opportunity to seek for education however, the disabled students are still isolated and placed in separate class. It is believed that special education could result in negative stereotypes towards students with disabilities in which they are perceived as different and less capable (i.e., incompetent and easier to be abandoned) compared to students without disabilities (Linton, 1998). These stereotypes are mainly caused by the medical model perspective in which disability is perceived as a problem in an individual and PWDs group as different from the communities. The medical model accounts discrimination as a problem faced

by individual with disability which suggests that PWDs must first overcome their disability in order to function in a particular society. Hence, with the need for the PWDs to be adaptable this creates a barrier in terms of social interaction and getting jobs (Scotch, 2000). In addition, PWDs are barred from being involved in education, health services, living place, transportation, recreation and social activities (Barnes and Mercer, 2004). As a whole, it can be concluded that PWDs are treated unfairly in every aspect of their life by the society (Barnes and Mercer, 2004).

Furthermore, the medical model is also influenced by the invention and the use of technology. Technology accurately reflects the concept which defines “normal” and reflecting life. PWDs are being isolated when they are not given access to any particular technology due to their disability. They will be able to use the technology and function again in the society only when the idea of them being fully healed and normal again is achieved. Therefore, with this kind of idea, PWDs are not viewed as normal individual and important member of the society which leads to negative stereotypes in the society. Most modern technology such as building constructions and products are developed without taking into account the capabilities and capacities of an individual (Scherer, 1996) thus affecting the ability of PWDs to access the available facilities.

The medical model perspective has brought attention to various issues which includes the emergence of social model of disability. Social model identifies any intended or unintended systemic barrier, negative attitude and exclusion from the society towards PWDs. Therefore, this proves the idea that society itself is the main factor that contributes to individual disability (Paley, 2002). Apart from that in the social model, PWDs are perceived as a minority group which frequently becomes the victim of discrimination, stigma, social alienation, oppression, isolation and various social barriers such as to participate actively in the community (McLaughlin and Kuno, 2011).

Developed countries such as United Kingdom and Japan have implemented the social model as one of the important aspects in the government policy for the purpose of enhancing the well-being of PWDs. Issue pertaining PWDs in Malaysia is viewed and influenced by the medical model or social model which needs to be known and studied. As asserted by McLaughlin and Kuno (2011) the medical model is rooted in the society nowadays and linked with capitalism and meritocracy which have been dominating the values of the world community. Therefore, the purpose of the current study is to explore the perspective of social-medical model of the disability among PWDs in Malaysia.

MATERIALS AND METHODS

Research design: In the present study, Grounded Theory Method (GTM) is applied as the research design. This study employs GTM to motivate the researchers to go into the life of the respondents as well as achieve new perspective from the world of the respondent in order to acquire a new discovery which could contribute to the existing knowledge (Strauss and Corbin, 1998, 1990). In this study, grounded theory enables the formation of social-medical model according to the perspective of PWDs in Malaysia which is derived from the data acquired using an inductive process.

Respondent: Overall, a total of 26 respondents are involved in this study. The respondents consist of a manager and three officers from the Social Welfare Department, five representatives from the persons with disabilities association, eleven PWDs (spinal cord injury, paraplegia, disabled and blindness) and three representatives of parents from children with disabilities association.

Procedure: Prior to this study, the research group has obtained the consent from the Social Welfare Department to conduct this study which involves different agencies and government departments. The respondents of the research have been chosen based on purposive sampling. The informed consent letter was given to the respondents before the interviews are conducted.

Data collection: In this study, the data was obtained using two methods, namely semi-structured interview and focus group discussion which lasted about 60-90 min. The semi structured protocol consists of open-ended question that was designed to explore different perspectives regarding the social model of disability from different groups, namely PWDs, people without disabilities and parents of PWDs. The interview protocol was designed based on the research objective and every interview was recorded and transcribed.

Data analysis: The data analysis process is conducted based on Strauss and Corbin (1990, 1998) procedure. The transcription is read line by line in order to effectively identify the concept during the open coding process. Next, the concept is grouped into category and sub category which are developed from the category of dimension. The category and sub-category are arranged using axial coding in order to develop an explanation regarding the phenomenon that is being studied (main category) as well as to identify the source of perspectives in social and medical model (source), the

barriers of social model (intervening conditions), the action/interaction (strategy) and the effect of action of the strategy (consequences). The final step involves selective coding with the aim of forming the main variable (main category) consisting of all data, whereby the category core that is systematically related to another category is chosen. The category and the association are merged during the process of selective coding to form a "story line" that describes "what is happening" in the phenomena that is studied.

RESULTS AND DISCUSSION

The main category of this study is the perspective of social-medical model of disability of the PWDs which comprises of acceptance, independence, equity, accessibility and the power to make decision. Apart from that the analysis results that are achieved using the GT method also yield the source of social model, challenge or barrier to the social model, strategy to face the barrier of the social model and the effect of social model on the PWDs life.

Social model principles: There are five main principles of the social model, namely acceptance, independence, equity, accessibility and power in making decisions.

Accessibility: The access to facilities, public places and government buildings is very crucial to the PWDs. One of the PWD respondents mentioned that the access to public facilities is very important for him to have an easy way of dealing with his daily life activities and needs:

"It's okay. As long as I can move everywhere. No barrier for me to walk everywhere. That is very important. I want to go to the Road Transport Department. Then, I want to manage my things first floor but no slope going up" (R19)

Power in making decisions: The power to make decisions is defined as the ability of an individual to make a decision independently. Mothers of disabled children are stressed with the importance of letting their disabled children to make their own decision without having their parents or others to decide for them. One of the views is quoted as follows:

"Where do you want to eat tonight? If she always says Kentucky Fried Chicken (KFC), then every time, always KFC. So my children very smart they want to go elsewhere they train her to say ok" (R12)

Equity: There are three types of equity, namely equity of access, equity of opportunity and equity of rights. The Equity of access states that all provided facilities for the community can be used by everyone regardless of their condition:

"Yeah but I think accessibility is very important to me. Although, it shouldn't be accessible but need to be accessible to many. So if accessible, whether you are handicapped or not, everyone can access" (R14)

Other than that, the equity of having job opportunity is also important. The point is further asserted by the Social Welfare Department officer:

"Not to mention the PWD, only have a certificate. Many came out will eventually come back to the Community Rehabilitation Centre. It shows that the PWDs community is facing a hard time to determine their life's direction and difficulty to get a job due to inequality imposed on them" (R15)

Independence: The desire to live independently without depending on other's assistance is very important to PWDs:

"The moment I got my car, then started to move. I think I only want to move forward from now on. In my workplace, I tell them I want to go back. I tell them I want to go back by my own" (R14)

Acceptance: The parents of disabled children must learn to accept the birth of their child regardless of the disabilities. The acceptance towards children with disabilities is very important for them to receive the right aids and supports from others to allow them to develop well:

"The immediate parents have to stand up accept that they have special children the children will be able to receive help to improve" (R11)

Social model source: In this study, the main source of social model is awareness which enables the implementation of the principles of social model in the life of PWD's and people without disabilities.

PWDs self-awareness: Self-awareness among PWDs is important to enable them to succeed and be permanent in the working world. For instance, a PWD mentioned that:

“We cannot make the disability as the barrier”
(R5)

This implies that a PWD should not regard disability as a factor that prevent them to be successful. Apart from that, PWDs need to strive hard to compete with people without disability in order to be accepted by any organisation:

“I am hardworking so the employer like me. For other people who are not hardworking, it's difficult to give orders and not creative. But I am more likeable... I told my friends if we get a job, we need to be disciplined, do it properly, the employer will like us, because we are hardworking, don't follow people that is not hardworking” (R5)

Society awareness: The society awareness includes the awareness towards the needs of PWDs. For instance, those employers who are not aware of the needs of disabled workers would not bother to provide a good access at the workplace for the ease of disabled worker:

“Right in front of my superiors, they did not even think of, I have fallen many times along the path” (R14)

Awareness of parent of children with disabilities: Apart from that, one of the Social Welfare Department officers mentioned the importance of parents of children with disabilities to be involved and fully support any programs for PWDs which are implemented by the government:

“...Like in the community, parents should be involved together. But parents did not support. It is better to have a social responsibility, from both mother and father.. There are lots of things we can do but this is the restraint. Now we already have job coach. Job placement for the PWDs but there are parents that unwilling to send their disabled children.. The problem is the parents..” (R15)

Barriers of social model: There are six barriers of social model, namely stigma, discrimination, in effectiveness of law, barrier, isolation and inequality.

Stigma: One of the stigma which is often related to PWDs community is that they are always perceived as disadvantaged group that is unable to contribute anything. For instance:

“...community has a stigma on the PWDs. People generally look down towards the ability of PWDs” (R9)

Other than the stigma towards the PWDs, it is important to note that the family members of PWDs are also stigmatised. The mother of a syndrome down child mentioned her view as follows:

“Social stigma, that came. Friends won't come to visit me. They didn't know how to respond. And I wanted people to ask me but nobody say anything” (R10)

Discrimination: One form of discrimination towards PWDs community is in terms of receiving education. It is difficult for PWDs to get the opportunity for education because the society believes that disabled individuals do not have to go to school due to their disability:

“It's the fault of the care giver, like if a disabled person is a child, he wanted to go to school but couldn't. Because the school did not accept a disabled person. It is not the child's fault. He wanted to go to school but the school refused. Is he different? He got the same brain but only has different physical. At least give him the chance to go to school” (R6)

Ineffectiveness of the law: There is no enforcement of the law to protect the PWDs community which has resulted in the cause of waiver and the abandonment of their rights. For instance as mentioned by one of the fathers of a disabled child, the breach of the Persons with Disabilities Act 2008 will not get receive any attention or action from the authorities:

“No penalty. As long there is no penalty, then they do not take into account. Because you spend more. No reinforcement” (R10)

Barrier: There are two types of barrier experienced by most of the PWDs, namely financial barrier and environment barrier. These barriers serve as the source of difficulty for the PWDs to receive their education, get married and achieve the necessities of life:

“I think if I get some extra money I want to further my study frankly, I currently have many girlfriends but I have many problems and burdens.. My income only enough to pay house rent” (R8)

“Our income is limited. A bit problem. Now I’m paying house rent. Wanted to buy but the cost is expensive. I want to apply for a license” (R16)

Isolation: The PWDs also experience isolation in terms of education and social life. The social isolation is caused by the low level of confidence among PWDs when they socialise with person without disability. For example, a proposal to establish a higher education institution solely for PWDs is a form of isolation for them:

“Ok its good. Through my experience. When all the blind people entered high school, everyone gets culture shock. It’s like we did not know the real world. Until we become really isolated. So, our confidence becomes low. When we entered a place for person without disabilities when no one approach us we are done” (R19)

“Why there is no university specifically for PWDs? It has everything, the university is for PWDs. Enough for scholarship, allowance, when come out from the university, we have a job opportunity. We have lecturers in the university” (R7)

“Isolation, no worries, he’s lack of knowledge, what is the advantage of PWDs card, he doesn’t know” (R7)

Inequality: There are two sub-categories that describe inequality, namely the inequity in terms of financial aid and unjust actions towards PWDs. For instance, one of the disabled people mentioned that the allowance for disabled people is supposed to be given to all disabled people regardless of their income. Apart from that, the unjust actions provided by the school is one of the reasons why PWDs are not able to get education like the person without disabilities:

“There are no criteria mentioned. This means that all criteria are the same. Household income not more than RM1, 200. I get so disappointed. That was the first if the government wants to give something to PWDs in Malaysia, give to all. Whether the income is one thousand, two thousand, just give the EPC. If your income is ten thousand, do you still want to go JKM (social welfare department) asking for RM300? What I want to say here is, PWDs with low income, why given no conditions? RM1200 not qualified but I think just give” (R6)

“So he couldn’t further studies. So he took SPM (national examination) from outside. I personally think that is unfair for a person in a wheelchair or any other PWDs just because he couldn’t, all opportunities were closed” (R6)

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Strategy: In the current study, the purpose of strategy is to address barriers of social model.

Getting knowledge: The information category is defined as any information related to the life of PWDs. Parents of children with disabilities need a lot of information on raising their children because raising a disabled child involves greater difficulty compared to raising non-disabled children. Therefore, it is believed by having the required information, parents would be able to overcome any obstacles in raising children with disabilities:

“I didn’t know what to do with my baby. I call people nobody I knew have a child with down syndrome... it was very difficult but I google a lot and I find that all conditions may be due to enlarged adenoid” (R12)

Getting support: Support is an important factor in PWDs community, especially receiving supports from peers, parents, professionals and institution. One of the disabled respondents mentioned that:

“Transfer me back to the St. Oliver Hospital. I can learn pyhsioteraphy, learn a bit about wheel chair. Whelly-whelly while having counselling” (R6)

Apart from that, one of the Social Welfare Department officers agrees that PWDs community should be provided with support from other individuals such as vocational training. With the presence of such support, it can help the PWDs to overcome the problem of barrier in terms of receiving education:

“Like I saw someone in Community College at Kuala Lumpur, they accept persons with learning disability. Programs...certificates... certificate is good. At least you are offered for skills. Because the academic certificate is limited. But vocational you can run... skill training... like for us with learning disability, we take hairdressing course” (R21)

Social model influence: The results of the study showed that the strategy which is used to overcome the barrier in social model provides a positive effect towards the PWDs life.

Well-being

Positive emotion: After receiving support from experts such as counsellors, the PWDs community has successfully reduced their stress mental health problems:

“I was mentally down. Very down. I also didn't expect this. So, like what Got stress But not long.. When after my operation, I went out from the hospital, I went.. They gave me counselling. From there, I could accept my condition that this disease will never be cured” (R14)

Other than that, after getting support from relatives, the PWDs would be able to get rid of the negative emotion such as low self confidence and self-esteem which provides them with the chance to succeed in their life:

“Because during that time, there is one guy in the village suffered from a spinal injury-Mr Licu. My uncle often came by to visit. Asking for news and giving encouragement.. His advice is really powerful. Like, he give an example, look at si anu-anu (describing somebody) how he works, doesn't mean that you are disabled, you should only stay home. Like there is no life anymore” (R8)

Negative emotion: A disabled person will not be able to accept his own condition if no support is given:

“He became crazy and committed suicide after the accident. There was no help support during that time. He was not from a wealthy family.. He helped his father make houses. When he fell and broke his waist, he could not accept the reality. Even his mother asked us for help to advise her son. But it was too late. He couldn't accept anymore and now became crazy” (R6)

Our study found that access to public facilities and infrastructure is one of the most important aspects in the life of PWDs. The inaccessible infrastructure has become the main barrier for the PWDs community to make any arrangements. Swainea and Labbe (2014) also reported the same results with four factors related to the physical environment which had an impact on PWDs, namely the shop design, external access for shopping malls, facilities and environmental condition. A good design of a building should take into consideration the accessibility to all consumers, regardless of their disabilities.

In terms of society awareness, it was found that the level of understanding concerning disabled and awareness towards the need of PWDs community are still lacking. Hence, PWDs often become the victim of discrimination and is frequently neglected (Juliet and Anselm, 2008) reported that the society awareness is still low in terms of understanding the true meaning of disability as well as the needs of PWD's. The lack of awareness is related to the negative attitude towards PWDs (Myers *et al.*, 1998). The acceptance towards PWDs community by the family and society is very important to avoid them from being isolated and marginalised. Pretty *et al.* (2002) found that those PWDs who are not accepted by the society would feel isolated and alone as well as having lack of social relationship which leads them to spend most of their time at home. In the current study, it was found that parents of children with disabilities as well as the PWDs themselves often receive negative stigma from the society. The parents of PWDs are considered as a bearer of misfortune by others for the 'deeds' they have done. Jahoda *et al.* (2010) also found that parents of children with disabilities are often stigmatised due to the society's belief which states that a child with disability is the punishment towards any offence that has been committed by the parents.

On top of that, the current study found that PWDs community often becomes the victim of discrimination, especially in receiving education. A study conducted by Mara (2014) discovered that PWDs find themselves being prevented from getting education in terms of lack of support in the learning process as well as lack of qualified staffs to monitor the PWDs educational progress. Other than that the current study also found that it is important to provide freedom to the children with disabilities in making their own decisions. This finding is contradictory to the finding achieved by Jahoda *et al.* (1988) which states that PWDs community is often neglected from having the rights to make their own choices.

The current study also found that having equity in accessing public facilities and building is very necessary. The inaccessible environment for every individual would

present a barrier for certain people. Sowney and Barr (2004) asserted that people with learning disability have poor health, stemming from the inaccessibility to get to the available health facilities. In terms of inequality in job opportunity, the findings of the current study are more or less similar to Greve's (2009) study which argues that there is a large gap in employment between the disabled workers and non-disabled workers. Other than that Curnow (1989) described that PWDs community is categorised as a low income group due to their unemployment and lack of working skills. The ability of PWDs to live independently without the help of others is found to be important in the current study. One of the ways to enable them to be independent is empowerment. Emener (1991) found that it is necessary to conduct a rehabilitation program in order to increase the PWDs self sufficiency and living independence.

The negligence of the rights of PWDs community was found to be originated from the absence of law enforcement to protect their right. It is vital for the law enforcement to ensure equal opportunity is received by the PWDs in terms of residential facility, employment, transportation, citizenship, government facility and telecommunication.

The support from government authorities and institutions towards PWDs community is very important to motivate them to be competitive and feel acceptable in the society. PWDs will continue to be regressed and left out compared to non-disabled people due to the absence of the right support. McAuliff *et al.* (2014) found the importance of empowering the PWDs community, particularly the low income group. Apart from that, employment support needs to be implemented by employers who have disabled workers (Pitt and Butterworth, 1995).

These supports indirectly disseminate positive impacts towards the well-being of PWDs. This is consistent with the findings achieved by Ferlis (2014) which states that support from spouse, peers, family members and rehabilitation centre are the source of subjective happiness among the PWDs. Apart from that Beresford and Clarke (2009) also found that receiving support in terms of inclusive activity plays a big role in increasing the well-being of PWDs.

The current study has provided several important implications. First is a proposal to improve the current policy of the Malaysian Social Welfare Department particularly in seeking a better method to solve PWDs humanity issues such as discrimination, isolation, prejudice and stereotype. The second one involves ensuring a greater focus towards fostering the well-being and the quality of life of the PWDs. Third is providing

awareness to society and institution authorities regarding the importance of applying the social model approach in the life of PWDs and finally, providing valuable information to government authorities through the Malaysian Social Welfare Department. It is worth to note that the findings of this study can only be generalised to the extent of Malaysian context because the data are derived only from the perspective of Malaysian community.

CONCLUSION

It can be concluded that the fostering of the social model of disability approach in the government policy can help in dealing with PWDs issues such as discrimination, stigma, inequality, denial of PWDs rights, prejudice and others. Apart from that the social model could assist in educating and giving awareness to the society regarding PWDs to ensure that they are treated as important members who are fully accepted by the society.

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