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Understanding Disability from the Views and Experiences of Taiwanese People with a Physical Disability

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Abstract: This qualitative study explores the experiences of 7 Taiwanese people with physical disabilities in Taiwan through three in-depth interviews with each participant. Despite disability legislation, participants identified experiences of community exclusion. We argue that their exclusionary experiences reflect embedded cultural attitudes and call for greater recognition of these influences to help foster inclusion of disabled people in Taiwan. Recommendations for researchers and policy-makers are provided.

Keywords: disability; qualitative research; Taiwan

Introduction

Taiwan is located in the middle of the Western Pacific festoon of islands; although its total area is only about 36,000 sq. km, it serves an important role as an East Asian crossroad (Department of Geography at National Taiwan Normal University, 2001). Today's Taiwanese society is a result of various cultural influences over a long period. In the 17th century, Taiwan had been occupied by Dutch settlers for 38 years (1624-1662). In 1661, the Ming Dynasty's Zheng Cheng-Kung defeated the Dutch and Taiwan was unified with China. Since then, an increasing number of Han Chinese from the southeastern coast of China immigrated to this nearby island, and during 1895-1945, Taiwan was occupied by Japanese settlers. In 1949, the Republic of China government withdrew from Mainland China and moved to Taiwan where it remains this day (Department of Geography at National Taiwan Normal University, 2001). Currently, the population in Taiwan is estimated at 23,483,793 (Department of Statistics Ministry of the Interior, 2015).

In Taiwan, the “People with Disabilities Rights Protection Act” (referred to simply as the disability legislation) is the most important social welfare policy for this group of people (Ministry of the Interior, 2009). It was enacted in 1980, and the latest amendment in 2015 aims to “protect the legal rights and interests of people with disabilities, secure their equal opportunity to participate in social, political, economical, and cultural activities fairly, while contributing to their independence and development” ("People with Disabilities Rights Protection Act," 2015). However, as a result of people’s preconceived ideas and the government's insufficient promotion of more enlightened attitudes, many Taiwanese people see disability as a punishment, and some fear that it might be contagious (Department of Social Affairs of the Ministry of the Interior, 1994; Holroyd, 2003; Huang et al., 2009). The stereotyped view of the Taiwanese public is to see people with a disability as being inferior to others. Therefore, for example, non-disabled people might think individuals with a disability are of no use to society because they need to be taken care by others for their entire life. Disabled people are expected to fight against the difficulties they encounter with great effort, rather than expect their community to make accommodations for them (Department of Social Affairs of the Ministry of the Interior, 1994; Holroyd, 2003). Thus, a common attitude toward disabled people is that they are objects of charity. Consequently, there are many instances of discrimination against disabled people, despite legislation against such discrimination (Department of Social Affairs of the Ministry of the Interior, 1994; Wang, 2002; Y. L. Wang, 2010a, 2010b). The inequitable treatment of people with disabilities in Taiwan means that they are more likely to be isolated and segregated, stigmatized and considered to be a disadvantaged minority (Hsieh, 1997; Wang, 2002; Yuan, 1981).

In Taiwan, the three strongest influences on the cultural understanding of disability are traditional Buddhist beliefs, Confucianism and the Chinese language, which all have significant impacts on Taiwanese values, attitudes and behaviors in the interactions that occur between the individuals and society (Berry, Poortinga, Segall, & Dasen, 2002; M. Y. Chang & McConkey, 2008; Charlton, 1998b; Huang, Fried, & Hsu, 2009; Iwakuma & Nussbaum, 2000; Miles, 1995, 2000, 2002; Shih, 1996).

Buddhist Beliefs as a Cultural Influence

Buddhist beliefs such as reincarnation and karma have an important influence on the cultural understanding of disability in this context (Holroyd, 2003; Huang et al., 2009; Miles, 2002). In Buddhism, reincarnation means people have cycles of lives and karma refers to how people's right and wrong conduct in the past influences their deserved happiness or their suffering in the present (Miles, 2000). Having a disability is seen as a type of temporary suffering in this existence because of personal wrongdoing in earlier lives. Being reborn disfigured or suffering humiliation in karma is more usefully interpreted as an educational force, making progress towards perfection rather than as a retributive destiny (Miles, 2000).

Confucianism as a Cultural Influence

Additionally, the Chinese family and relationships among its members have been deeply affected by Confucianism. As Holroyd (2003) states, parents, influenced by Confucian teachings of a duty-bond obligation to be a "right and proper" person (p. 4) and of "bringing honor and avoiding disgrace to the family" (p. 5), expect their children to become successful people in society and bring honor to their own family (Chou, 1998; Holroyd, 2003; Kuo &

Kavanagh, 1994; Shih, 1996; Szalay, Strohl, Fu, & Lao, 1994). Therefore, having a child with a disability challenges the traditional philosophy of Confucianism in several ways. First, having a disabled child disturbs family harmony, because he or she cannot be expected to conform to social and cultural norms, such as how to behave respectfully and appropriately (Holroyd, 2003; Huang et al., 2009). Secondly, parents of adult children with a disability cannot expect their offspring to care for them in old age. They also have to take care of their adult children for longer than would otherwise be necessary, a situation that challenges the Confucian notions of reciprocity and parent-child obligations (Holroyd, 2003). Having a disabled child is therefore seen as a shameful thing for many Chinese families because the family is apologetic to its ancestors; having such a child also implies unsuccessful social performance because it does not meet the cultural expectation of bringing honor or reputation to the family (Yueh Ching Chou, 1998; Holroyd, 2003; Huang et al., 2009; Iwakuma & Nussbaum, 2000; Mink, 1997; Shih, 1996). The belief that disability stems from supernatural causes leads to two extremes in attitudes toward disabled people: “Either overprotectiveness or discrimination” (Iwakuma & Nussbaum, 2000 p. 242). Such is the case also in Taiwan. On the one hand, new-borns with a disability in Taiwan might lack care and love, because their family members are ashamed of having a disabled child, and thus feel that they have lost face. On the other hand, a disabled child might be overprotected by their family members, because of the strong obligation of family ethics to look after their disabled family member (Holroyd, 2003; Iwakuma & Nussbaum, 2000; Kuo & Kavanagh, 1994; Shay, 1990; Shih, 1996; K. Y. Wang, 2002).

Language as a Cultural Influence

One of the keys to understanding attitudes toward disability in a specific culture is language (Charlton, 1998a). Charlton (1998a) states that “the words used to describe disability are loaded with social connotations” (p. 66). Stone (1999) says that in Chinese culture “both impairments and illness are constructed as products or signs of imbalance: internal imbalances of yin and yang, heat and cold; external imbalances in family and social relations, between ancestors and descendants, spirits and mortals, rulers and subjects” (p. 140). Moreover, many Chinese characters with offensive meanings that are used to refer to people with a disability, such as “idiot”, “simpleton” or “mad person”, contain animal radicals or components related to evil spirits or lifeless objects (Stone, 1999). This use of dehumanizing and Otherness-creating symbols signifies the cultural attribute of intolerance and non-acceptance of disability within Chinese culture (Stone, 1999). The interlacing of the influences of traditional Buddhism, Confucianism, and language has led to the cultural understanding of disability in Taiwan where people with a disability have tended to be excluded from their own culture, because of the negative perceptions towards disability.

The Need to Investigate the Views and Experiences of Taiwanese People with a Physical Disability

While there is a growing body of research in Taiwan on disabilities, most studies have focused on people with intellectual disabilities and their families. For example, Chou and other co-authors (2007) applied Cross-Cultural Quality of Life Indicators to understand the life quality of adults with intellectual disabilities who live with their families in Taiwan. Their findings suggest that although many people with intellectual disabilities live in the community, they are isolated and segregated with their perceptions of social inclusion scoring at the lowest level. Furthermore, Chou, Pu, Lee, Lin and Kröger (2009) studied how aging female family carers of adults with an intellectual disability or mental illness perceived the impact of stigma on their life quality in Taiwan. These authors applied four scales to measure the carers' perceived stigma, health, social support and quality of life. They found perceived stigma had the most negative impact on quality of life for these two groups of aging, female carers.

Yet, while the number of registered disabled people in Taiwan is increasing each year (in 2012, the Monthly Bulletin of Interior Statistics identified 1,104,849 people with disabilities accounting for about 4.75% of the overall population) it is people with a physical disability who account for the largest group of the disabled in Taiwan, with those that only have a single physical disability accounting for around 34% of the total, and those having multiple disabilities accounting for 10%.

Vehmas (2004) points out the importance of listening to the lived experiences and perspectives of people with a disability for conceptualizing a realistic understanding of disability. He says:

> "The way people without impairments view people with impairments and their chances for well-being and good life inevitably is based on their experience and point of view as nondisabled persons. Thus, when defining disability, without hearing the subjective voices of those seen as disabled, we can only construct an external, the kind of 'objective' model that does not explain much of individuals' experiences – it would merely be a projection, 'our' view of 'them'" (p. 220).

Thus, the need to explore in depth the everyday lived experiences of people with a physical disability, living in the Taiwanese cultural environment is essential to a deeper and wider understanding of their lived experience of disability in this context (Chiu & Han, 2010; Lin, 2012). The purpose of this study is to explore the views of individuals with a physical disability in Taiwan about their ordinary everyday lives with a disability in the community, and to have these views acknowledged.

This study was approved by the Human Research Ethics Committee of Queensland University of Technology in Australia.

Methods

Sample

The main aim of this study was to explore the understanding of disability from a Taiwanese perspective, based on the views of disabled people. In line with this research aim, purposive sampling was used to locate and recruit participants from two non-government disabled welfare organizations in two counties of Taiwan. Researchers used purposive sampling to locate particular types of people for in-depth investigation (Neuman, 2004). Purposive sampling facilitated the exploration of a deeper understanding of a specific field of study which the participants (with their experiences as a person with a physical disability living in Taiwan) were able to provide, rather than representing the larger population of this group of people. Participants were invited from two disability organizations. Interested participants were then invited to contact the first author directly by return mail, e-mail, or phone call. A total of seven native participants took part in this study, and have been given the following pseudonyms: Pearl, Joyce, Hilda, Venice, Judy, Yugo and Mary. All participants either lived in urban areas, or shifted between rural and urban areas. Background information on the participants is given in Table 1.

Table 1: Background information of the seven participants

Participants	Gender	Physical Disability	Age	Job (Full time)	Institutional -ized Experience	Living situation
Pearl	Female	Poliomyelitis	In thirties	Office clerk	Yes	Alone
Joyce	Female	Muscle Fibrosis in left leg	In twenties	Office clerk	No	Family
Yugo	Male	Cerebral Palsy	In twenties	Student	No	Family
Mary	Female	Poliomyelitis	In fifties	Booking clerk	Yes	Family
Hilda	Female	Spinal Cord Injury	In sixties	None	No	Family
Judy	Female	Poliomyelitis	In fifties	None	Yes	Family
Venice	Male	Poliomyelitis	In fifties	Running a shop	Yes	Alone

Procedure

After obtaining each participant's consent, the first author conducted three in-depth interviews with each participant. She interviewed each participant once a week for as long as it could match their schedule. She also allowed sufficient time between interviews for participants to think about what living with a physical disability means to them and reflect on the issues raised in the interviews. The interviews lasted from one and half hours to three hours and were held at participants' homes, as agreed to by both the first author and the interviewees. This ensured the participants' comfort and control of the interview process. Member checking (Creswell, 2007, 2013) was used to assist the credibility of the findings, and was undertaken by the first author with study participants following each interview session to see whether the interviewer's understanding of the information obtained in the previous interview session was correct. With the participants' agreement, the interview was audio-recorded and then transcribed.

Analysis

The grounded theory approach was adopted to guide the data analysis process with its emphasis on beginning inductively and returning to the data deductively to construct a unique understanding of living a life with a physical disability from the perspective of the study participants (Charmaz, 2003, 2006). In line with Charmaz (2003), the interview data were coded to identify central themes, patterns, ideas, and concepts existing within the data (Hesse-Biber & Leavy, 2006). Furthermore, memo writing was used extensively throughout the data analysis process to elaborate emerging concepts and to stimulate new ideas by reading through and sorting memos (Charmaz, 2006; Hesse-Biber & Leavy, 2006). Writing and comparing memos continuously throughout the research process helped the researchers to remain immersed in the analysis and to discover concepts (i.e. categories and their subcategories) which were able to reflect the interview data. This process, in turn, led to an increase in the level of abstraction of the analysis (Charmaz, 2006).

Results

With the focus of the present study on presenting participants' understanding of disability from their lived experiences and views of living with a physical disability, the grounded theory "it is more than just the impaired body" developed from a wider study is not included here, but interested readers can refer to Lin, Knox, and Barr (2014) for details.

The findings showed participants felt excluded from society because of their physical disability, and spoke of their desire for greater inclusion. Specifically, grounded in participants' views and experiences of living with a physical disability in Taiwan, three themes were identified by the researchers. These are described below.

The Importance of Social Networks

The participants raised many issues in relation to their social relationships in the interviews, with the three main relationships being family relationships, friendships, and intimate relationships. Firstly, the family played a key role for most participants in supporting them to live their life as a person with a physical disability in a way they wanted to. Because the participants felt excluded from other non-disabled members of their communities, they felt terrified at the prospect of living without family support. Sustained family support was thus the most significant form of support in many of the participants' lives, and the loss of this was seen as a disaster. For example, Mary lost significant family support because of the death of her husband and the growing up and moving away of her children. In addition, aging was making her body even weaker. She said, "If no one is here, what should I do!?" [Mary's emphasis, sounding anxious]. Although the participants wanted to have sustained family support, they also expressed two concerns. The first one was becoming a burden. For example, Hilda very poignantly pointed out the following situation with her daughters, "Now…they are encumbered with financially assisting me. They also need to eat and to raise their children." The second concern was about losing their current support. Yugo and Joyce relied heavily on their parents' support. However, they understood that this would be gone after their parents died. As Joyce said, "It is impossible to depend on them my whole life."

The participants also shared many of their experiences of, and perspectives about, friendship. Some stated that they felt happy and could get support from their friends. For example, Yugo stated, "I enjoy very happy and lively interactions with them!" In contrast, some participants said they felt lonely because they lacked friends. For example, Pearl talked about a lack of friendships. She said, "In my heart, I feel friends are far away from me and I don't have friends." Participants with good friendships stated that these friendships were based on the qualities of reciprocity and companionship, so they could receive emotional and physical support from their friends. For example, Yugo described reciprocity as follows: "They help run errands for me and lift me in and out of the car. And I help them with their assignments. Sometimes I also have to play a role as a psychological counsellor to resolve their emotional problems." Some participants stated they made efforts to manage their friendships, and others encountered many difficulties in developing such relationships.

In addition to the common experience of being excluded from friendship, participants reported that they experienced great difficulties in building intimate relationships. For example, after Joyce experienced having a short intimate relationship with a non-disabled boy, and absorbed the social attitudes from people around her, she found this prospect had been hampered by her disability:

> "My mum said if my foot were not like this, I might fall in love very easily.

> Because I have heard it for a long time, if my foot were not like this today … perhaps I would have a boyfriend waiting for me already. Perhaps I would have already walked into the church to get married."

As for the further development of a romantic relationship into marriage, participants felt that such a relationship was unlikely with a non-disabled person. For example, Venice stated that, "A handicapped person marrying a non-handicapped individual divorces easily!" More specifically, the participants saw considerable difficulties in developing intimate relationships, because they felt that non-disabled people saw them as a burden and/or as asexual. Venice recalled how a non-disabled person questioned his sexual ability. He recounted, "He asked me, 'If you went to…a red-light district, how would you do it?!'...So the handicapped like us also give people a feeling. You are all out of order!" Therefore, intimate relationships seemed the most difficult kind for most of participants to develop, with Joyce noting sadly, "I think it is a thorny path!"

Little Support from Disability Legislation

The participants also stated that one of the factors influencing the way they understood disability was disability legislation in Taiwan, with their views on this being marked by feelings of economic insecurity and a general lack of support. First, the participants stated that their employment rights were not guaranteed by the legislation, and noted that many employers in Taiwan would rather pay a penalty than hire a disabled individual. Yugo stated, "A boss might not care about this disability legislation and he won't care if he is fined!" Furthermore, several participants were hired full-time and got job equal to their education levels. They asserted that they experienced significant inequalities at work because of their disability. For example, Mary did not get equal payment for her work, adding that, "I am low-cost labor!"

The second reason why the participants felt that disability legislation in Taiwan was not very useful was that it provided limited support. Participants identified limitations such as lack of accessibility, unfair resource distribution, lack of awareness of available support, and an inefficient bureaucracy. For example, Joyce mentioned several times in the interviews that she felt official attitudes were always bureaucratic and did not really aim to help people with disabilities. She stated, "I always think the Act is . . . manipulated by the upper level administrators." The participants thus considered that they were excluded from greater economic and social participation in Taiwan.

Cultural Attitudes Towards Their Disability

A few participants pointed out that they felt more accepted by Taiwanese culture now than they had in the past because of improved social attitudes towards people with a disability. For example, Yugo said, “I definitely heard that [disabled people were useless] before! But that was an idea before! Now I can’t say it doesn’t exist, but fewer and fewer people have such an idea now!” However, overall the participants stated that they felt rejected by, and excluded from, their culture much more than accepted by it. The cumulative discrimination that they experienced inevitably led to their not feeling accepted or valued in Taiwanese culture. When discussing cultural understanding of disability, the participants stated that they experienced discriminatory and distressing attitudes from non-disabled people. For example, Pearl found many parents of non-disabled children did not accept people with a disability. She told of her experience of going to a supermarket. “Parents will pull their children away when we are around.” The participants noted that others would often use abusive language with them, seeing their disabilities as a punishment due to karma, as well as seeing them as inferior to able-bodied people. For example, Joyce felt uncomfortable about how non-disabled people tended to use unpleasant words for her, noting that she had been called “a cripple [and] a lunatic, which is offensive language.”

Implications

Enhancing Inclusion of People with Disabilities in Taiwan

Before further discussing the implications of this study, some limitations should be acknowledged. First, these findings should not be generalized to all Taiwanese people with a physical disability, as they may apply only to the study participants. Furthermore, the issues of gender, ethnic, and age-related experiences, the differences between those individuals with congenital or acquired disabilities, and the experiences of those who live in institutions rather than in the community, as well as people with a broader range of disabilities, were not specifically addressed in this study.

The lived experiences of participants’ social networks, their views on disability legislation, and experiences of cultural attitudes toward their disability showed their understanding of disability in Taiwan, and together can explain how they feel excluded from society. Firstly, the participants stated how having a disability significantly influenced the development of important social relationships. For example, Pearl felt that she did not have access to friendship, while Joyce did not have access to intimate relationships. These individuals thus experienced great isolation, loneliness, and lack of support from the communities in which they lived. The participants all expressed a desire to be included in the wider community, but also stated that they had difficulties in interacting with others because of how people reacted to their disabilities. While living their lives within the Taiwanese context, participants experienced the negative attitudes towards them such as prejudice and discrimination that are common across many cultures, regardless of cultural differences (Swain, 2004). As Shakespeare (2006) notes, people with a disability are usually less likely to be well integrated into social networks and friendship circles, and thus tend to "experience significantly greater isolation and loneliness" (p. 170). Shakespeare (2006) further argues, "Even where disabled people have friends and companions, they may find it harder to experience everyday intimacies which non-disabled people take for granted" (p. 173).

Building and sustaining social relationships are fundamental principles of inclusion (Bigby & Frawley, 2010; Chenoweth & Stehlik, 2004; Clegg, Murphy, Almack, & Harvey, 2008; Reinders, 2002). However, in disability research there has been limited discussion of friendship, sexuality, or loneliness, and much of the research which has dealt with these issues relates to people with intellectual rather than physical disabilities (Lin, 2012; Shakespeare, 2006). Thus more research is needed to find out how best to increase the social inclusion of people with physical disabilities.

As for reducing discrimination against disabled people in Taiwan, while the Taiwanese government has passed legislation that aims to achieve this, most of the participants felt that it was ineffective in practice, with it still being very difficult for them to find employment. The deep-rooted cultural prejudices against people with disabilities that exist within Taiwan thus remain a significant blight on the lives of such individuals (Grech, 2012; Meekosha & Soldatic, 2011). Their experiences and views of the economic insecurity in Taiwan reflected the most common experience of living with a disability in the world, which is poverty. In the modern world, employment is a significant aspect of adult identity, and it is no exception for people with a disability. However, many disabled people are unemployed, underemployed, and underpaid, resulting in extreme poverty for their families (Grech, 2008, 2012; Priestley, 2001).

Taiwan and the UN Convention on the Rights of Persons with Disability (CRPD)

With the global trend to emphasize human rights for people with a disability, such as enforcing the UN Convention on the Rights of Persons with Disability (CRPD) in 2008, perceptions of disability have been changing, and there is now growing support for greater community participation by people with a disability (Barnes & Mercer, 1995; Chang, 2007; Hayashi & Okuhira, 2006; Hsieh, 1997; Jayasooria, Krishnan, & Ooi, 2006; Kim, 2010; Oliver, 2009). Indeed, Kim (2010) argues that "the CRPD has placed people with disability on the global agenda, highlighting their need for greater inclusion in society and recognising them as citizens to be valued and respected" (p. 103). The inclusion of people with a disability has thus become recognised as a global issue. The spirit of CRPD is to see people with a disability as having the same human rights as those without disabilities, and it aims to change the disability policy paradigm from one of exclusion to inclusion (Melish, 2007; K. Y. Wang, 2008b). CRPD argues that people with a disability should be valued and respected (Kim, 2010), and it is a move "toward a 'social' or 'human rights' model that focuses on capability and takes inclusion, individual dignity, personal autonomy and social solidarity as the principle points of departure” (Melish, 2007, p. 8).

However, Wang (2008b) finds that, in practice, disability legislation in Taiwan remains far from the spirit of CRPD. She argues that rights for people with a disability in Taiwan refer to how they get subsidies, services or payments, and thus the related private groups and many disabled citizens tend to focus on this. This shows that while the government does aim to provide this group of people with support on an individual basis, it does not work to make society more accessible to all citizens (Melish, 2007), as the participants in the present study experienced. Exclusion is still a common experience. Moreover, this type of disability legislation often ensures that people with a disability must depend on social welfare, thus diminishing the control that they have over their own lives (Abberley, 1995; Hughes, 2002). The interlacing of Buddhism beliefs, Confucianism, and language in Taiwan forms the negative cultural attitudes towards disability, which the legislation in Taiwan struggles to deal with. Thus, discrimination is embedded in and permeating these people’s everyday lives (Oliver, 2009).

This reality is quite different from the spirit of CRPD, which sees rights for people with a disability as an ethical and moral issue (K. Y. Wang, 2008b). Although Taiwan is not a member of the UN, it must also work to ensure that human rights of people with a disability are recognized. More specifically, the government must aim to see improving the rights of people with a disability as a broader societal responsibility and obligation (K. Y. Wang, 2008a, 2008b). According to Article 8 of the CRPD , one of the ways to achieve this is by “initiating and maintaining effective public awareness campaigns” (Committee on the Rights of Persons with Disabilities, 2008). Kim (2010) emphasized that “without effective and organized political representation of people with disability, such important policies may remain as merely “intended” policies, or lack legal binding even if adopted” (p. 110). The League of Welfare Organizations for the Disabled has been the voice of Taiwanese people with disabilities. It advocates for their rights and welfare by demanding legislative change and raising public awareness (H. H. Chang, 2007; Shieh, Chang, & Huang, 2005). The groups working for people with a disability in Taiwan should continue to monitor how the human rights of people with a disability are being protected, and help to identify any substantive concerns in this regard (Melish, 2007; The League of Welfare Organizations for the Disabled, 2009). Studies such as the present one provide a critical forum for the voices of individuals with a physical disability to be heard and for their knowledge to be valued so their concerns can be effectively reflected to policy and practice provision. Advocating rights for people with disability via political participation campaigns and related research can ensure that the voices of people with a disability are heard. Their voices can become the basis for highlighting the upholding of their human rights and thus provide the opportunity for greater social inclusion both in Taiwan and other parts of the world.

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