

Chinese Immigrant Mothers of Children with Developmental Disabilities: Perceived Stress and Social Support

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CHILDREN'S DEVELOPMENTAL DISABILITY AND FAMILY CHALLENGES

Developmental disabilities (DDs) constitute a significant portion of children's disability. In 2001, among the nearly 18,000 children with a disability in Canada, 57.6% of them had DDs (Statistics Canada, 2001). DDs include a set of abilities and characteristics that differ from the norm in the limitations they impose on independent participation and acceptance in society. DDs can refer to individuals who have for example intellectual disability, autism, Down syndrome, fragile X and other developmental delays. Families of children with disabilities experience impacts on all aspects of their life. For example, mothers caring for children with disabilities experience increased stress and anxiety, change in employment status, marital strain, and report having more health problems compared to those without children with disabilities (Dowling & Dolan, 2001). Prolonged stress may create health and mental health risks and lead to deterioration in their physical and mental health (Sarafino, 1994).

WHY IS THIS RESEARCH NEEDED?

Canada's population comprises a diversity of cultures. Between 2006 and 2011, among the 1,162,900 foreign-born people who immigrated to Canada, roughly 122,100 newcomers were Chinese in 2011, and the Chinese population constitutes the second largest visible minority group in Canada, making up 4% of Canadian population; there are 537,060 Chinese population in the Greater Toronto Area (Statistics Canada, 2010). Among Chinese immigrants are some families who are raising children with disabilities. To



date, limited attention has focused on the perceived stress and social support among Chinese immigrant mothers of children with DDs. Therefore, this qualitative study (Chinese Immigrant Mothers Project) was conducted to fill the gap in knowledge.

Chinese Immigrant Mothers Project aimed:

1. To examine the effects of perceived stress and social support among Chinese-Canadian immigrant mothers of children with DDS.
2. To describe the types of stressors which impact their lives.
3. To explore the buffers that help them to access the needed services.

HOW WAS DATA COLLECTED?

This descriptive qualitative study (Sandelowski, 2000, 2010) used semi-structured interview approach to conduct in-depth interviews with 15 Mandarin speaking Chinese mothers (14 face-to-face and 1 telephone interview). All interviews were carried out in Mandarin. Participants were recruited from the Greater Toronto Area through one community organization. Questions explored mothers' stress, facilitators to social support, and Chinese traditional cultural beliefs. Transcripts were translated to

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English and a portion was back-translated to Mandarin to determine accuracy of translation. Our analysis was guided by House's (1981) conception of social support.

MAIN FINDINGS

There were a total of 17 children with DDs. The average age of children was 8.6 years with a range of 4 -19 years old. Mothers reported the following types of DDs among their children: 10 boys and 4 girls had Autism; 1 boy had Pervasive Developmental Disorder; 1 boy had Global Developmental Delay; 1 girl had a Learning Disability. All mothers had immigrated to Canada from People's Republic of China. The mean age of mothers was 37.7 years and their length of residency in Canada was about 9 years.

POSITIVE EXPERIENCES OF SOCIAL SUPPORT

1) Some mothers talked about their satisfaction and ease when they received funding from the government, and selected services.

My son got funding from government, I used them to choose some better services centres by ourselves ... Some training programs included speech therapy, language, behaviours and temper therapist for one and half year, lot of help from them....they also offered some life training programs to increase their life skills, such as "cleaning house", "go shopping", "go swimming", "go to the library", in this way, parents have some resting time. (Mother 5)

2) Some mothers expressed their appreciation and satisfaction when they received support and better services from health care, school, church, family, and friends.

My son's pediatrician is very responsible and nice.... Family members and friends provided lots of support. The church we regularly go to let us feel lots of love and helps us a lot, my son has one to one care in the church and he can do some paper crafts and activities. (Mother 3)

POSITIVE CULTURAL BELIEFS

All mothers indicated that they did not have the "reciprocity thought" which refers to the belief that parents provide services when their children are young and children will return respect and care for their parents when parents are old. Most of the mothers did not want to hide their children's situation from others.

I don't have the traditional Chinese belief of the "reciprocity thought" since my son is in this situation, I only hope he has skills and can be independent and make a living by doing the simple job in the future. I hope that his younger sister will take care of him in the future when parents pass away. This is my big concern to worry so much about his future. I don't have the feeling of loss of face, I told others honestly and hope others understand, I don't hide my family situation, face the reality and positively find the solutions. Caring and helping are very important, I won't give up and won't feel regret for all the sacrifice and contribution. (Mother 11)

PERCEIVED STRESSORS

Participants expressed their life challenges and stressors in accessing services for their children with developmental disabilities. The challenges discussed by some of the mothers included:

- limited financial resources
- occupational unemployment

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- excessive paper work
- long waiting times
- lack of English-language proficiency
- limited knowledge of social services
- emotional strain
- discrimination
- transportation difficulties and dispersed services
- mothers being blamed
- feelings of loss of face
- avoiding talking about family situation

Financial Insecurity, Long Waiting Time and Occupational Problem

Financial constraints limited accessing treatments (e.g. speech therapist, assessment from psychologists). Mothers also talked about their frustration with long waiting times to receive funding and services. Most mothers were facing unemployment and occupational changes, which created more financial difficulties.

Transportation Difficulties to Access the Dispersed Services

Transportation was a major concern and was a barrier to accessing the dispersed locations of service agencies for their children with DDs.

...available services scattered all over the place. I had to transfer the buses, subways to allow my daughter to get some program training and treatment. But each class took me so long to get there and go back...very challenging and felt exhausted. (Mother 15)

Emotional Strain

Many mothers whose children were newly diagnosed with DD experienced feelings of shock, pain, psychological pressure and depression. They had lack of emotional support since they did not have the extended

family and had limited social networks. Some mothers experienced emotional strain because their children received discrimination in public places.

I have so many worries in public since my son loves running all over the places and bother others. (Mother 8)

Most people don't understand autism, when we go shopping, taking the elevators, people like to watch with a different look and receive no priority to line up. (Mother 15)

Mothers Being Blamed

Some mothers got blamed from children's father and their families after their child's birth with a disability. Some fathers even left the families. Mothers were under immense stress.

I was blamed by my family members at the beginning that I might not take good care of my son, lack of social interactions with others for my son might be one of the reason, also was blamed for not bringing him to play with others, because my son was very introverted.(Mother 13)

Feelings of Loss of Face and Hiding the Child's Situation

Some Chinese immigrant mothers of children with DDs were still holding the traditional cultural views and greatly cared about their "keeping face". They believed their children's situation resulted in them "losing face" and, thus, did not reveal that information to the public nor to their friends and family.

In public places, I have much more concerns, others were watching us, I felt very uncomfortable and embarrassed. However, when I am in private place, it is fine. (Mother 8)

I do not want to be made some negative judgments by others. I would rather hide this family situation and save my face. I do not want to talk about this too much. (Mother 10)

HOW CAN INFORMATION FROM THE MOTHERS PROJECT BE USED?

The findings of the Chinese Immigrant Mothers Project provide understanding about mothers' health, well-being, and experiences of their families of children with DDs. The findings can be used by policy makers, program planners, school board leaders, clinicians, and community organizers to improve and develop culturally and sensitive family – oriented services. The findings may also be helpful to Chinese immigrant mothers to access relevant services and advocate for positive cultural beliefs in Canada for their children.

SELECTED REFERENCES:

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ABOUT THE INFORMATION SHEET

This information sheet is a summary of our recently completed qualitative study, which explored the stressors, facilitators, and traditional cultural beliefs that Chinese immigrant mothers encounter in accessing services for their children with developmental disabilities. For further information, please email to owhchair@yorku.ca with the subject heading 'Chinese Immigrant Mothers Project Report.'

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ABOUT THE RESEARCHERS

Dr. Chang Su is a Lillian Wright Postdoctoral Fellow in Maternal Child Health at the Faculty of Health at York University and the Principal Investigator of this study. She conducted all the interviews for this project. Dr. Nazilla Khanlou is an Associate Professor at York University and holds the Womens' Health Research Chair in Mental Health, she is the postdoctoral supervisor of Dr. Chang Su. Dr. Nasim Haque is a Senior Research Associate at the Office of Women's Health Research in Mental Health, Faculty of Health, York University.

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