

Wong Kear Kyii, 2017

Volume 3 Issue 2, pp. 1558-1570

Date of Publication: 17th October, 2017

DOI-<https://dx.doi.org/10.20319/pijss.2017.32.15581570>

This paper can be cited as: Kyii, W. (2017). Empowering Approaches by Chinese Parents of Special Need Children. *PEOPLE: International Journal of Social Sciences*, 3(2), 1558-1570.

This work is licensed under the Creative Commons Attribution-Non-commercial 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc/4.0/> or send a letter to Creative Commons, PO Box 1866, Mountain View, CA 94042, USA.

EMPOWERING APPROACHES BY CHINESE PARENTS OF SPECIAL NEED CHILDREN

Wong Kear Kyii

Faculty of Education and Social Science, University of Selangor, Shah Alam, Malaysia
wongkearkyii@hotmail.com

Abstract

There is a large variation in the experience of caring for special need children. The objective of this study was to identify the empowering approaches of Chinese parents related to their caregiving experience. 17 Chinese parents from 16 families whose children are attending a private school and a learning centre were interviewed in this study. A semi-structured face-to-face interview was used and responses were coded using grounded theory to identify themes of empowering approaches. Being cognitively and psycho-emotionally grounded enables Chinese parents to make sound decisions. The overwhelming needs related to caring for their special need child impel them to remain pragmatic when making appraisals. Their concern about the future of their child urges them to adopt a proactive approach. Interventional services aimed at helping Chinese parents to care for their special need child should include initiatives of empowering them to adopt positive approaches. Future research should look into the effectiveness of these approaches when adopted by novice parents.

Keywords

Special Need Child, Chinese Parents, Empowering, Grounded, Pragmatic

1. Introduction

Discovering that a child has a disability often is an unexpected and stressful event for parents. It is a bitter pill for many parents, especially for those who always expect their children to be outstanding. Although research has shown that appropriate support and resources could help parents cope with the challenges presented by their children, studies conducted in Malaysia portrayed a rather negative scenario. In a study that assessed the stress level of Malaysian parents of ADHD child, Narkunam, Hashim, Sachdev, Pillai, & Ng, (2014) concluded that the stress level among Malaysian parents was higher than their Western counterparts.

Parents vary in their parenting styles, concerns, approaches, values, involvement, and backgrounds (Taub, 2006). A comparison among parents from different ethnics, revealed that in Malaysia, non-Malay parents (Chinese, Indian and other ethnic group) are four times more likely to be stressed than Malay parents (Narkunam *et al.*, 2014). In addition, according to the 3rd National Health and Morbidity Study (Ministry of Health Malaysia, 2006), Chinese had the highest prevalence of psychiatric morbidity. These findings seem to suggest that Chinese parents of special need children are more susceptible to parenting stress. In view of these alarming facts, this study is intended to understand how some Chinese parents navigate through this formidable journey to position themselves and gain strength to move on.

2. Research Objective

This study seeks to identify empowering approaches demonstrated by well-adapted Chinese parents. The objective is to assist other parents to overcome the sense of helplessness commonly experienced by them while providing care for their special need child.

3. Scope of Study

This study is carried out among Chinese parents who have a child with identified hidden special needs such as ADHD, ASD and learning disability. Parents whose child is identified as gifted or physically handicapped are not included in the study.

4. Literature Reviews

4.1 Theoretical Cognitive Model of Stress and Coping

The theoretical cognitive model of stress and coping developed by Lazarus & Folkman (1984) has been used by Quine and Pahl (1991) to illustrate the interaction between the well-being of parents of children with special needs and the stressors. Within this model, two types of resources have been identified: personal coping resources and socio-ecological resources. The former include physical and mental health, personality, beliefs and adaptability, interpersonal, problem-solving and parenting skills whereas the latter include informal (partner, relatives, community) and formal network which can offer practical, emotional, material and financial support. These resources influence the coping strategies they adopt, namely, emotion-focused coping strategies and problem-focused coping strategies. Emotion-focused coping strategies wrestle with how the person feels about the stressor while problem-focused coping strategies deal directly with the stressor and its impact. Essex, Seltzer, & Krauss (1999) found that mothers who coped with their child's disability using problem-focused coping experience experienced less burden and depression than those who employed emotion-focus coping strategies.

4.2 Attribution Theory

Attribution theory is a perceptual approach to attitude formation. Although it is inadequate to limit causal attribution to efforts and innate ability (Lin, Wu, Chen, & Huang, 2016), it does explain, within its parameter, how individual makes inferences to the causes of events or outcomes of dispositions. The causes can be subsumed within two-dimensional taxonomy: an internal-external (locus) dimension, which locates the cause within the person or in the environment, and a stable-unstable (stability) dimension which identifies the cause as one that is chronic or transient (Weiner, 1972). When applied to caring for children with special needs, attribution theory provides explanatory evidence of how parents adopt coping strategies based on the two-dimensional taxonomy. The following table illustrates how parents attribute to causes of stressors.

Table 1: *Attribution Theory Applied to Approaches Adopted by Parents*

Locus / Stability	Stable	Unstable
Internal	Heredity	Inadequate knowledge
External	God's will / Fate	Insufficient facilities / Programmes

Parents who attribute stressors or limitations of their child to external and stable factors such as God's will, are usually more skeptical about intervention strategies as they tend to believe that there is nothing much they can do to help their child to improve. On the contrary, parents who attribute improvement of their child to internal and unstable factors will always feel more positive about intervention programmes, believing that these programmes could help their child to improve. Lustig (2002) found that families who could reframe the disability in a positive way and perceived themselves as competent rather than passive had better family adjustment. When parents are trained to attribute deficiency to internal, unstable factors, they will feel that they are able to meet the challenges of raising a child with special needs.

4.3 Theory of Learned Helplessness

The conceptual framework of attribution theory is closely linked to a behavioural deficit termed as learned helplessness. According to Peterson & Seligman (1984), learned helplessness is an expectation of uncontrollability that is generalized to new situations to produce the recurrence feelings of deficits. The sense of helplessness commonly leads to passivity, cognitive and emotional deficits, and even depression. Parents who show symptoms of learned helplessness will gradually presume that no interventions could possibly change the future outcomes of their child. Learned helplessness is in fact a denial of a person's need for personal control. Such attitude reflects psychological escapism where parents choose to deny their desire for personal control based on their perceived inability. Parents who provide chronic care for special need child could easily develop prevailing sense of hopelessness. Services will be of little importance to these parents as their emotional burden (sense of helplessness) has not been addressed adequately. It is no wonder that in Malaysia, there is a high "dropout" rate in the utilization of rehabilitative services by parents of special need children (Amar-Singh, 2008).

4.4 Empowerment through Services

Some findings revealed that a lengthy, complex, and discouraging assessment and diagnostic process could result in parents feeling confused, disempowered, and overwhelmed. Thus, follow-up services and continued support for these families are necessary components to help families adapt and meet their and their children's needs (Banach, Iudice, Conway, & Couse, 2010). Parents feel empowered when they are provided with support, information, resources, and tools for navigating the complexity of service/treatments. For example, parents' whose child undergoes Applied Behaviour Analysis (ABA) treatment report feeling empowered by the

training they receive (Dillenburger, Keenan, Gallagher, & McElhinney, 2010). Besides, parent–professional partnership will greatly enhance parental empowerment if a protocol for practice is offered to them, including specific clinical guidelines (Mulligan, MacCulloch, Good, & Nicholas, 2012). Receiving needed services will enable parents to make changes in their patterns of involvement and participation which lead to empowerment. (Itzhaky, & Schwartz. 2010).

5. Methods

17 Chinese parents from 16 families were invited to take part in this study. These parents have a child who is attending a community school or a private learning centre in two locations, Kuching and Puchong. These children have been diagnosed as having special needs such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactive Disorder (ADHD), Dyslexia, Asperger Syndrome, Dyspraxia and Learning Disability. These parents were informed of the purpose of the interview prior to scheduling an actual interview. All the interviews were conducted face-to-face. All ethical guidelines were applied to this study and prior consent was sought and acquired. Particular attention was given to the purpose of the study, confidentiality, anonymity and informed consent. Parents provided consent for the interview to be audio-taped.

6. Data Collection

A semi-structured interview was used in order to obtain insights into the coping strategies of parents of special need child. There were two parts of the interview. The first part covers parents' demographic information, child's case and age when diagnosed. The second part is about the approaches they adopt in dealing with the challenges of raising a child with special needs. For example: "What were your reactions when you were informed of your child's diagnosis?" "How does your household income influence your decisions when you are considering therapies for your child?" "In what ways does your religion help you to raise a child with special needs?" "How does caring for your child affect your social life?" "What form of help do you wish to receive which you believe will lighten your burden?" Each interview lasted between 30 minutes to 45 minutes. All the interviews were transcribed verbatim and coded.

7. Analytic Approach

The transcribed responses were analyzed using grounded theory procedures to explore themes (Strauss & Corbin, 1998). This qualitative approach promotes research that moves from what is seen and heard to an unexplored abstract understanding. Data were extrapolated to identify the dominant approaches which characterize coping attitudes grounded in the data (Chamberlain, Camic, & Yardley, 2004). The analysis in this study underwent sentence-by-sentence examination of what the parents had reported. The content of each statement was given a conceptual code. Similar codes were categorized into themes to provide an explanation of the approaches parents have cultivated over the years which help them to positively cope with the stress related to raising a child with special need.

Table 2: *Table of Coding*

Open Coding Categories	Axial Coding Paradigm			
	Causal Condition	Core Category	Strategies	Consequence
Options of therapies	Indecisiveness	Autonomous decisions	Be grounded Be pragmatic Be proactive	Empowerment
Emotional disturbances				
Financial constraints	Feeling of limitedness			
Demanding caregiving				
Concerns for future	Preparedness			
Elimination of discrimination				

8. Results

8.1 Parents Profiles

All the respondents have one child with special needs. One family is a single parent family. Of the 16 families, 13 of the families (81.3%) have either one or both parents received tertiary education. 8 of the families (50%) are dual-earners families. It is noteworthy that the rest used to be dual-earners families as well. The mothers in these families chose to resign from work in order to provide better care for their child. When the child was diagnosed as having special needs, the age of the parents was between 32 to 49 years old. 15 families have at least one of the

parents who is a professional. 11 of the families (68.8%) have a total income above the average household income according to the report of household income and basic amenities survey 2014 (Department of Statistics, Malaysia). All the parents are believers of either Buddhism or Christianity.

8.2 Be Grounded

On learning that their child has a disability, different feelings, such as shock, anger, fear, guilt, confusion and disappointment flooded the mind and heart of these parents. Of this constellation of emotions, they had to wrestle with the gripping fear of unknown. “Doctor, can you spell the word for me?” a mother whose child was diagnosed as having dyspraxia asked the physician for clarification in order to know the special needs of her child. Most of the parents did extensive read-ups to obtain a clearer picture of the special needs of their child. “Knowing the actual condition of our child enabled us to deal with his extraordinary behaviours unconditionally,” a father explained.

Having obtained a diagnosis, parents are to make decisions on therapies. These parents demonstrated resoluteness in seeking professional helps. However, looking for available therapies is very different from absorbing these added demands. “I have spent most of my saving on my girl. But I know this is what I have to do for her,” a single mother recounted. Besides financial strain and time demands, the fact that the effectiveness of these therapies often calls into question is another factor that complicates the process of decision-making. “Some of them are quacks,” a mother dismissively said.

Nevertheless, whatever actions taken by these parents to face the challenges, they are cognitively and even spiritually grounded. “Though my son has special needs, he is a gift from God,” remarked one of the mothers. They make informed decisions to overcome helplessness and despair.

8.3 Be Pragmatic

The special needs of children propel these parents to diligently scout about available therapies. Such extensive sourcing sometimes presents itself as a secondary stressor. First, sourcing itself demands sacrifices of time, energy and money. “Once, I drove for hours just to take my daughter to do therapies. On my way back, I was so exhausted that I had to pull over my car just to get some rest by the roadside before continue driving. I would do anything I could to help my daughter.”

Second, deciding on therapies requires these parents to take many factors into consideration. They mull over the demands on financial resources (Baker-Ericzen, Brookman-Fraze, &Stahmer, 2005). “Taking him for therapies is like throwing money to the doctors.” It is no wonder parents easily succumb to the feeling of helplessness when they feel that their limited financial resources would deprive their child of much needed therapies.

Unlike many parents who rely much on intervention services, these parents dispense financial resources and adjust their time in a pragmatic manner. “We did not send him for all the therapies because we could not afford. I did not resign. But I negotiated with my boss to allow me to work at flexible hours.” “Do what is necessary within our ability.” “We must do whatever that is within our ability to help them.” This pragmatic approach enables these parents to set attainable parameter of their care-giving. When parents reframe their care-giving positively (Ylven, Bjorck-Akesson, &Granlund, 2006), they could avoid burnouts.

8.4 Be Proactive

These parents initially focussed on the needs of understanding and rehabilitating their child. However, they realized that it was barely enough. “This is the reality. We must plan for his future.” Most of these parents are now more concerned about the future needs of their child. To them, nothing is more important than grooming their child to lead an independent life in future.

“We are really worried about his future. Who will take care of him when we are not around?” The majority of the parents shared such common worry. Though this concern may sound rather over-reactive, it explicitly reveals parents’ desire in protecting their disadvantaged child. “We are saving up as much as possible for her future.” “I have purchased a few insurance plans for her.” These parents believe that their child will have one fewer thing to worry about if their future financial need is taken care of. Established financial freedom is believed to lower the possibility of being discriminated by an intolerant society which offers special need children little space for social adjustment (Malik & Umi Kalthom, 2015).

“I know that no matter how much we save up for her is not enough. Besides, she needs someone to manage the fund for her. We want her to be able to make a living with her own hands. ”“We hope she will develop her interest to become a career.” These parents plan proactively for their child because they want them to experience a fulfilling adulthood.



Figure 1: *Empowering Approaches*

9. Discussion

There has been substantial literature on parenting stress and coping strategies with emphasis on making interventional services available in order to reduce their stress level. Nevertheless, a study conducted by some Malaysian psychologists found that parents whose children have been in contact with the PAC Unit (Psychiatry Adolescent and Child) for two years or more are actually more stressed than those whose children have two years or less duration of contact (Narkunam *et al.*, 2014). To optimize the effectiveness of the available service, it requires parents to adopt adaptive approaches and attitudes. This study identified some approaches that empower Chinese parents to remain positive towards all interventional decision.

One of the causes of parenting stress is linked to having no control over a situation. Like all parents who would do anything for their children, the parents in this study exhaust their ability to lay out an anchor to whirlwind. They have demonstrated that being cognitively and psycho-emotionally grounded enables them to deal with deficiency of their child and help them to balance the needs of their child and normal functioning of family.

Besides uncontrollability, confronting uncertainties is another paralysing experience. Extensive sourcing makes the process of rationalization rather complicated. If a parent assents

the demands unduly, it will lead to perceived inability and helplessness. Parents who are asked to implement strategies that outsource them will experience greater level of secondary stress (Johnson, O'Reilly & Vostanis, 2006). It is vital to advise parents of special need child to be pragmatic when deploying their resources lest the cohesiveness of family be jeopardized.

Lastly, parents' effort and desire for saving for a rainy day must not be dismissed as being worrywarts. Realising that their child's deficiency will have negative bearing on their future, they do not want to leave their future to chances. Of course, their ultimate desire is to help their child to master some survival skills. Much like the parents of normal child, they do envision a future of employment for their children (Blustein, Carter, & McMillan, 2016).

These approaches affirm the validity of attribution theory. Parents who perceive the deficiency as internal and transient tend to take positive steps to overcome sense of helplessness. Intervention service providers should therefore look into initiatives to focus on aspects of caregiving that promote greater parental control (Neely-Barnes & Dia, 2008).

10. Limitations

All the Chinese parents who took part in this study are from urban areas. Thus, the sample carried some selection biasness and may not represent all Chinese parents of children with special needs. In addition, these parents have a total household income higher than average Malaysians. They can afford to consider more options of intervention service and therapies. Parents with lower income may experience other struggles which are not addressed in this study. Lastly, with an over-representation of more educated parents in the sample, the responses reflect the propensity of more knowledgeable parents.

11. Conclusion

Child maladaptive behavior is associated with parents' increased burden and stress (Saloviita, Italinna, & Leinonen, 2003) as well as poor efficacy in parenting (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Therefore, helping a child with special needs should include efforts that help the parents to feel empowered. Service extended to parents of special needs children should strive to enhance their parenting efficacy, rather than increasing their burdens. Varied professional advice may cause greater confusion and lead to loss of parenting bearing. Services that reinforce parental inefficacy should be re-evaluated as they can easily become secondary stressors especially when what parents feel they need to do for their children

contradict professional advice. Only interventions that encourage parental autonomy in decision-making could sustain long-term commitment of care-giving.

References

- Amar-Singh, H. S. S. (2008). Meeting the needs of children with disability in Malaysia. *Med J Malaysia*, 63(1), 1-3.
- Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities*, 30, 194-204. <https://doi.org/10.2511/rpsd.30.4.194>
- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social work with groups*, 33(1), 69-83. <https://doi.org/10.1080/01609510903437383>
- Blustein, C. L., Carter, E. W., & McMillan, E. D. (2016). The voices of parents: post-high school expectations, priorities, and concerns for children with intellectual and development disabilities. *Journal of Special Education*, 50(3), 164-177. <https://doi.org/10.1177/0022466916641381>
- Chamberlain, K., Camic, P., & Yardley, L. (2004) 'Qualitative Analysis of Experience: Grounded Theory and Case Studies', in D. F. Marks and L. Yardley (eds). *Research Methods for Clinical and Health Psychology*, pp.69–89. London: Sage.
- Department of Statistics Malaysia. (2015). *Report of Household Income and Basic Amenities Survey 2014*. Retrieved from https://www.dosm.gov.my/v1/index.php?r=column/cthemByCat&cat=120&bul_id=aHh1THVWNVYzTFBua2dSUIBRL1Rjdz09&menu_id=amVoWU54UT10a21NWmdhMjFMMWcyZz09
- Dillenburg, K., Keenan, M., Gallagher, S., & McElhinney, M. (2010). Autism: Intervention and parental empowerment. *Child care in practice*, 8(3), 216-219. <https://doi.org/10.1080/1357527022000040426>
- Essex, E. L., Seltzer, M. M., & Krauss, M. W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal on Mental Retardation*, 104, 545-563. [https://doi.org/10.1352/0895-8017\(1999\)104<0545:DICEAW>2.0.CO;2](https://doi.org/10.1352/0895-8017(1999)104<0545:DICEAW>2.0.CO;2)

- Itzhaky, H. & Schwartz, C. (2010). Empowerment of parents of children with disabilities: The effect of community and personal variables. *Journal of family social work*, 5(1), 21-36. https://doi.org/10.1300/J039v05n01_03
- Johnson, R. F., O'Reilly, M., & Vostanis, P. (2006). Caring for children with learning disabilities who present problem behaviours: a maternal perspective. *Journal of Child Health Care*, 10(3), 188-198. <https://doi.org/10.1177/1367493506066480>
- Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, 50, 883-893. <https://doi.org/10.1111/j.1365-2788.2006.00906.x>
- Lazarus, R. & Folkman, S. (1984). *Stress appraisal and coping*. New York: Springer.
- Lin, C. H., Wu, S. F., Chen, Y. J., & Huang, M. K. (2016). The effects of causal attribution on academic performance. *PEOPLE: International Journal of Social Sciences*, 2(1), 738-751.
- Lustig, D. C. (2002). Family coping in families with a child with a disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 37, 14-22.
- Malik, S., & Umi Kalthom. (2015). PEOPLE: International journal of social sciences. *Role of special education curriculum in adjustment of physically handicapped children in society*. 1(1), 904-911.
- Ministry of Health Malaysia. (2006). Report of the Third National Health and Morbidity Survey (NHMS III). Institute of Public Health, Kuala Lumpur.
- Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: A model for partnering with parents of a child with autism spectrum disorder at diagnosis and beyond. *Social work in mental health*, 10(4), 311-330. <https://doi.org/10.1080/15332985.2012.664487>
- Narkunam, N., Hashim, A. H., Sachdev, M. K., Pillai, S. K. and Ng, C. G. (2014), Stress among parents of children with attention deficit hyperactivity disorder, a Malaysian experience. *Asia-Pacific Psychiatry*, 6, 207–216. <https://doi.org/10.1111/j.1758-5872.2012.00216.x>
- Neely-Barnes, S. L. & Dia, D. A. (2008). Families of children with disabilities: a review of literature and recommendations for interventions. *Journal of Early and Intensive Behaviour Intervention*, 5(3), 93-107. <https://doi.org/10.1037/h0100425>

- Peterson, C., & Seligman, M. E. (1984). Causal explanations as a risk factor for depression: Theory and evidence. *Psychological Review*, 91(3), 347-374. Retrieved from <http://dx.doi.org/10.1037/0033-295X.91.3.347>
- Quine, L. & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: a test of Lazarus' Transactional Model of Coping', *Journal of Community and Applied Social Psychology*, 1(1), 57-70. <https://doi.org/10.1002/casp.2450010109>
- Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model. *Journal of Intellectual Disability Research*, 47, 300-312. <https://doi.org/10.1046/j.1365-2788.2003.00492.x>
- Strauss, A. & Corbin, J. (1998). *Basics of Quantitative Research*. London: Sage.
- Taub, D. J. (2006). Understanding the concerns of parents of students with disabilities: Challenges and roles for school counselors. *Professional School Counseling Journal*, 10(1), 52-57. <https://doi.org/10.5330/prsc.10.1.b0mkn7k57w583266>
- Weiner, B. (1972). *Theories of motivation: From mechanism to cognition*. Chicago: Rand-McNally.
- Ylven, R., Bjorck-Akesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 253-270. <https://doi.org/10.1111/j.1741-1130.2006.00089.x>