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Preliminary Results Report

Parental Stress in Parents of Children with Physical Disability in Hong Kong

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Foreword

The researcher of the present study is a person with congenital muscular dystrophy, a kind of serious, life-long and incurable neuromuscular disease which causes progressive loss in physical ability and shortened life span. I rely heavily on my mother’s care for my day-to-day living due to my physical disability. I am truly thankful that I have a supportive and warm family; and my mother is an optimistic woman who always wears smile on her face despite the fact that she has to take care of a disabled daughter for the whole life since my birth. My family is full of joyful moments. Nevertheless I can feel that taking care of a disabled child can indeed result in great physical and emotional strain in the caregivers. Therefore I would want to investigate the parental stress and other related psychological factors among the caregivers, so as to try to suggest some ways to help enhancing the psychological wellbeing of the caregivers despite handling stress from day-to-day caregiving.

On 6th October, 2011, there was a news article about a girl with server muscular dystrophy who failed to apply for a place in residential care home for disabled persons. Her mother mentioned, “… I love my daughter very much, but I am very worried that no one can take care of my daughter as I am getting older…” From the news article we can know how severe physical and psychological strain can be seen in the parents. In fact, it was not the first time that similar situations happened in Hong Kong.

Promoting the overall well-being (physical and mental) of people should be regarded as an important social issue. “People” here should include people with and without disabilities, and their caregivers. The above reasons have contributed to the origin of this research project, which aims at studying the parental stress, affiliate stigma, and related psychological constructs, among the parents of children with physical disability (PCPD). Thanks for the funding support from the I.CARE Programme (Research and Studies) 2011/12, the present study is hoped to generate meaningful findings for raising awareness of caregivers’ situation in the society, and formulating better rehabilitation and social services in Hong Kong.
The process of conducting this study was a fruitful and meaningful experience to me. Although it was very demanding for me to handle the research tasks, course assignments and examinations within the same period, I have gained much valuable experiences from this research study which deeply inspired me. It has further ignited my passion of pursuing research career in the future to promote the psychosocial wellbeing of people with disability. First of all, I gained a first-hand experience of conducting a psychological research through which I have learnt many new knowledge and skills. I really enjoyed the moments I conducted the data entry and analyses in the lab with my dearest lab members.

The most touching and inspiring part was the response from the participants (the parents of children with physical disability). Here are some examples. “Please teach me, because I want to give you a more useful data that helps you generate better results”, said by some parents who gave me phone call and asked me to teach them how to complete the questionnaire. “I am very happy to finally see someone is aware of our (caregivers’) situation. Thank you for conducting this study”, written by a parent at the end of the questionnaire. Some other parents have offered me suggestions on how to improve the research design such that more useful data would be obtained. All these responses have greatly kept me motivated in conducting this research. I am very grateful for the parents’ support and participation.

Most importantly, from this research, I have gained more understanding of the caregivers’ psychological wellbeing. I have become more aware of the social resources and policies regarding the wellbeing of the caregivers. Finally, this study reminds me that the unconditional love from parents to their children is one of the most precious things in the world. I am very thankful for having my parents who are always willing to offer me love and care endlessly. My family is warm and supportive. I will always cherish their love and care.

Parental Stress in Parents of Children with Physical Disability in Hong Kong

Introduction

Although giving care to the child is part of the responsibility of the parents, the
situation becomes entirely different when the child is diagnosed a disability and may rely on long-term dependence on daily living (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu, & Wood, 2005). It is because parents have to manage their children’s chronic health problems as well as the requirements of everyday living. Take muscular dystrophy, a common cause in children with physical disabilities, as an example. Muscular dystrophy is serious and incurable neuromuscular disease characterized by progressive physical disability and shortened life span (Hinton, Nereo, Fee, &Cyrulnik, 2006). Parents of children with muscular dystrophy, especially mothers, experience significant chronic emotional stress which influences the overall management of the illness; and offering life-long care on the children’s day-to-day living would lead to parental strain (Chen, Chen, Jong, Yang, & Chang, 2002; Nereo, Fee, & Hinton, 2003).

PCPD experience disability-related caregiving stress and stigma due to being affiliated with their children living with physical disability, which may negatively impact their mental health. Caregiving is a dynamic and dyadic process in which the children’s adaptation to the disability and outcome of treatment would be significantly related to the quality of caregiving and interactions; and these would in turn depend on the caregivers’ adjustment to the child’s disability condition and the resulting parental stress (Knussen&Sloper, 1992; Lessenberry&Rehfeldt, 2004; Oyebode, 2003).

Social support was found in many past studies to be mediator between chronic parenting stress and psychological outcome, leading to better adjustment to child's disability and the caregiving (e.g. Barakat&Linney, 1992; Erikson & Upshur, 1989; Friedrich & Friedrich, 1981; Quittner, Glueckauf, & Jackson, 1990). A study by Green (2003) showed that stigma perceptions held in mothers of children with disability would increase maternal distress, consistent with Goffman (1963) that stigma not only affects those who have that stigmatizing attributes but also other people who are affiliated with them, such as their parents and friends. On the other hand, self-compassion has been found to be associated with
enhanced psychological health (Neff, 2003). However, the role of self-compassion in the coping with disability-related parental stress has less been studied.

Aim of the Study

The present study aimed at studying the relationship among the parents’ parental stress, social support, courtesy stigma, affiliate stigma, self-compassion, positive thinking, and mental health. At the current stage, some preliminary analyses have been conducted. In addition, a model of relationship among parental stress, affiliate stigma, social support, and mental was proposed and tested by modeling statistical analyses. The results of this proposed model have been presented at the Hong Kong Psychological Society Annual Conference in June 2012. We are continuing to test the dataset by more stringent analyses on the variables.

Method

Sampling

PCPD were recruited from special schools and non-governmental organizations (NGOs) from January to April 2012. Invitation letters were sent to local special schools and NGOs. Three special schools and four NGOs agreed to participate in the study. Consent form, questionnaire and return envelopes were distributed to the parents through these organizations. Total 131 completed questionnaires returned. This made up the final sample.

Participants

The respondents (78.6% female) had a mean age of 45.4 years (SD = 6.83, range = 19-70) and their children with physical disability (42.7% girl) had a mean age of 12.9 years (SD = 3.99, range = 3-20). The majority of the diagnosis of the children’s physical disability was cerebral palsy (26%) followed by muscular dystrophy (15.3%). Majority of the respondents were married (82.4%) and received secondary 4-5 education (40%).

Measures

Demographics. Demographics information of the respondents was obtained, including age, gender, marital status, occupation, education level, and relationship with the
Child's functional independence. The 10-item Barthel Index (Department of Health, Taiwan) was used to assess ten areas in the child’s performance in activities of daily living as perceived by the parents. The ten areas included feeding, bathing, grooming, dressing, fecal incontinence, urinary incontinence, toilet use, transfer, walking, and climbing stairs. The internal consistency of this scale in the present study was .861 in Cronbach’s alpha.

Parental stress. Perceived disability-related parental stress was measured by the 40-item Parents of Children with Disability Inventory (PCDI; Noojin & Wallander, 1996) on a 6-point Likert scale. It measures how often the parents would worry about four domains of the child disability-related parental stress, including 1) Medical and Legal Concerns; 2) Concerns for the Child; 3) Concerns for the Family; and 4) Concerns for the Self. The higher the total score, the higher the level of stress. A sample item for domain 1 is “My child needs another surgery”. The internal consistency of this scale in the present study was .936 in Cronbach’s alpha.

Social support. The family and friends subscales (4 items each) of the 12-item Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988), and 4 self-constructed items were used to measure the parents’ perceived availability of social support from 1) family, 2) friends, and 3) the community rehabilitation network. The internal consistency of the whole combined measure in the present study was .922 in Cronbach’s alpha. The internal consistency of the 4-item self-constructed subscale on community rehabilitation network was .842 in Cronbach’s alpha.

Courtesy stigma. The 7-item Devaluation of Consumer Families Scale (Struening et al., 2001) was used to measure courtesy stigma experienced by the parents on a 4-point Likert scale. A sample item was “Most people look down on families that have a child who
Parental stress in parents of children with disability. The internal consistency of this scale in the present study was .732 in Cronbach’s alpha.

**Affiliate stigma.** The 22-item Affiliate Stigma Scale (Mak & Cheung, 2008) was used to measure the level of internalized stigma among the parents on a 4-point Likert scale. A sample item was “I feel inferior because I have a child with physical disability”. The internal consistency of this scale in the present study was .888 in Cronbach’s alpha.

**Self-compassion.** The 26-item Self-compassion Scale (Neff, 2003) was used to measure the level of self-compassion among the parents. It included three components, namely self-kindness, common humanity, and mindfulness. Items were measured on a 5-point scale. A sample item was “When times are really difficult, I tend to be tough on myself”. The internal consistency of this scale in the present study was .818 in Cronbach’s alpha.

**Positive thinking.** The 26-items from the Kansas Inventory of Parental Perceptions (KIPP; Behr, Murphy, Summers, 1992) was used to measure the parents’ positive thinking towards the caregiving for the child with physical disability. Items were measured on a 4-point Likert scale. A sample item was “My child is why I am a more responsible person”. The internal consistency of this scale in the present was .887 in Cronbach’s alpha.

**Mental health.** The 18-item Mental Health Inventory-18 (MHI-18; Ritvo et al, 1997) was used to measure the mental wellbeing among the parents on a 6-point Likert scale. A sample item was “Have you been a nervous person within this month?” The internal consistency of this scale in the present was .939 in Cronbach’s alpha.

**Procedure**

Parents were invited to complete a questionnaire about their child's functional independence, stress level, social support, their perceived level of courtesy and affiliate stigma, self-compassion, positive thinking related to caregiving, and mental wellbeing. Informed consent was sought from each participating parents before completing the
questionnaire. Stamped return-envelopes were provided for returning the signed consent form and completed questionnaire. It was clearly stated that the participants can withdraw from the research anytime once they feel uncomfortable. They were anonymous when filling in the questionnaire. Their personal information was strictly kept confidential.

Preliminary Results

Demographic items

Pearson’s correlational analyses showed that the age of child and parents were not significantly correlated with any of the variables of interest. For the gender of child and parents, t-tests showed that there were no significant differences between the means of the variables between female and male. By one-way ANOVA, all the variables, except self-compassion, did not differ significantly among the different marital status. Self-compassion differed significantly among the different marital status. One-way ANOVA also showed that all variables, except affiliate stigma, did not differ significantly among the different educational level. Affiliate stigma differed significantly among the different educational levels. For the child’s functional independence level, Pearson’s correlational analysis showed that it significantly correlated with parental stress, self-compassion, and mental health.

The above results indicated that none of the main variables of interest was associated with the age and gender of the parents and child. However, self-compassion was associated with the marital status of parents and the child’s functional independence level. Affiliate stigma was associated with the education level of parents. Parental stress and mental health were also associated with the child’s functional independence level.

The main variables of interest

Significant correlations were found among all the variables, except positive thinking which did not have significant correlation with parental stress.

Parental stress was positively correlated with courtesy stigma and affiliate stigma; but
negatively correlated with social support, self-compassion, positive thinking, and mental health. However, inconsistent with the hypothesis, parental stress was not significantly correlated with positive thinking. Social support was positively correlated with self-compassion, positive thinking, and mental health; but negatively correlated with courtesy stigma and affiliate stigma. Courtesy stigma was positively correlated with affiliate stigma; but negatively correlated with self-compassion, positive thinking, and mental health. Affiliate stigma was negatively correlated with self-compassion, positive thinking, and mental health. Self-compassion was positively correlated with positive thinking and mental health. Positive thinking was positively correlated with mental health.

In addition, parental stress and affiliate stigma were the partial mediators between social support and mental health. Parental stress was a partial mediator between social support and affiliate stigma.

**Discussion**

This present report discussion has only dealt with some preliminary results. More advanced statistical analyses and discussions are still undergoing. It also aims at proposing and testing some specific relationships among the variables of interest, such as model testing.

From the preliminary results, it indicated that the higher parental stress would be associated with higher affiliate stigma. Affiliate stigma is when the courtesy stigma is internalized in the PCPD. It implied that PCPD not only have to cope with the caregiving stress, but also the experience of being stigmatized by the public due to being affiliated with their children with physical disability. This would seriously affect the wellbeing of the PCPD, as shown in the negative correlation between parental stress and mental health, and that between stigma and mental health. However, since correlation only implies association, but not the causation between the two variables. Regardless of the direction of causation between parental stress and stigma, the results of the present study demonstrated the need for rehabilitation services to address the negative impacts of different aspects in parental stress,
and also the stigma perceptions among the PCPD. It also pointed out the importance of social support to the wellbeing of PCPD.

Specifically, we could observe that the subscale “concerns for the self (the parents)” in parental stress had the highest mean score, and was the most highly correlated with courtesy stigma, affiliate stigma, and mental health, comparing with the other three areas of concern in parental stress. Concerns for the self (the PCPD) include PCPD's personal feelings and fears particularly about the future, additional responsibility and time demands due to caregiving, and concerns over reactions of others (Noojin & Wallander, 1996).

It could imply that not only the current caregiving situation would be a stressor, but also the possible situations in the foreseeable future. It is because PCPD generally have to keep paying attention to any changes in the health conditions of their children and the family wellbeing every day. Moreover, what causes them great distress is that they usually keep worrying whether there is someone to take care of their disabled children if he/she sudden gets sick, or as he/she is getting older. PCPD may also feel anxious about the public acceptance of their disabled children, and this in turn relates to the courtesy and affiliate stigma felt by PCPD. These implied that the PCPD's own thinking towards caregiving and the future would be an important determinant of the psychological wellbeing of the PCPD.

The present study has obtained evidences for the negative impact of stigma on the mental health among PCPD. It also addresses the need for a new perspective of stigma reduction in our society. While the awareness of reducing stigma towards disability is becoming higher in our society nowadays, the focus has generally been put more on the people with disability instead of their caregivers/affiliated people. In fact, caregivers and people closely affiliated with people with disability may also experience courtesy stigma. This not only brings negative impacts on their wellbeing, but also their relationship with the people with disability. It is obviously found in caregiving. Green (2003) found that higher courtesy stigma felt by presents was associated with lower communication with age peers in
the parents' disabled children. Caregiving is a dyadic relationship. The wellbeing of the parents (the caregivers) and the children would mutually affect each other. Therefore, the present study suggested that it is essential to reduce stigma felt by PCPD.

The present study provided evidence for the positive effect of social support on the psychological wellbeing of PCPD, which is consistent with many past researchers. The present study showed that social support led to better mental health partially because social support reduced parental stress and affiliate stigma. Moreover, social support led to lower affiliate stigma partially because social support reduced parental stress, which then leading to lower affiliate stigma. Among the three sources of social support (family, friends, and community), and the effect of family support was the most important. Family members could offer both emotional and instrumental support to the caregivers. For instance, family members could mutually share happiness and sadness, let others rely on mutually when facing problems, and share the responsibility of caregiving. The cohesiveness and harmony among family members would let the caregivers feel that they are not alone, and that they could together discuss and make adjustments to the family functioning when needed. In this way, a happy family life can be established regardless of the caregiving burden. This is essential to one's quality of life. This can also help reduce the "concerns of the family" in parental stress, and affiliate stigma, leading to better mental health among the PCPD.

In addition, family support has the highest mean score which implied that the PCPD received largest support from family; while they received relatively less perceived support from the community. Community support basically includes support from the community rehabilitation network, the mutual support among the caregivers in the community, and the support services provided by the rehabilitation organizations. There could be many possible reasons for the relatively lower score in community support. For instance, PCPD may actually be not aware of the support services offered; the existing support services do not pinpoint the need of PCPD; and the effectiveness is not high enough. Therefore, the present
study indicated the necessity for the government and NGOs to increase support services to the PCPD since community support is also an important source of social support.

Suggestions to the Rehabilitation and Social Service

There are different areas of concern in parental stress. Specific strategies are needed for relieving different concerns. Apart from professional support from medical professionals for relieving stresses related to the health conditions of the disabled children, the role of social service organizations (SSO) is significant. SSO can form "caregivers groups" for PCPD to mutually express their emotions and worries such that other caregivers and/or social workers can listen to and respond to their concerns accordingly. Professionals can help parents establishing positive thinking towards caregiving. SSO is also suggested to offer PCPD the resources on the life-planning of children with disabilities to let PCPD know about and plan ahead how the life of their disabled children can be in the future. This may help relieve the "concerns for the child" among PCPD, thereby lowering parental stress. In addition, it is suggested that the government could offer more financial support for SSO to provide "daytime/temporary caregiving service". This helps relieving the great stress due to the perception of being "the only full-time available and suitable caregiver for my child".

Apart from organizing activities specifically for PCPD and their family, SSO can organize more activities, such as carnivals, which encourage direct contact and cooperation between families with and without members with disabilities. Through direct contact, mutual understanding and inclusion could be enhanced, and then it would gradually help reduce stigma towards PCPD and their family. In addition, SSO can actively encourage PCPD in the community to form "advocacy groups". Members not only exchange support and information themselves; most importantly, they are encouraged to actively organize advocacy activities which aim at raising the awareness of people with disabilities and their family in the society. Examples of such activities would be PCPD sharing of their life experience, workshops and promotional board displays. It is hoped to achieve empowerment and therefore affiliate
stigma reduction among the PCPD. As for the role of SSO, SSO could function as the organizational and instrumental support for these advocacy groups.

Family harmony and cohesiveness should be emphasized when designing activities for PCPD and their family. SSO are encouraged to design activities that can let family members understand how they can share the responsibility and demands of the caregiving, so as to enhance the cohesiveness. This would not only increase family support for the PCPD, but also lower the "concerns for family" in parental stress among PCPD. Moreover, since family plays an essential role in the wellbeing of PCPD, SSO should pay attention to the family situation when providing services/counselling to the PCPD and their disabled children such that optimal help that can pinpoint their need could be offered.

To enhance community support, suggested ways include: 1) organizing workshops on caregiving issues such as the correct lifting techniques and stress management for the PCPD; 2) provision of comprehensive and latest rehabilitation/support resources and information; 3) provision of professional consultation, counselling, and referral services for PCPD and their family; and 4) inviting PCPD to participate in the design and operation of the activities provided for PCPD, such that the services can really pinpoint their needs and concerns.

**Future Research Direction**

Several future research directions are recommended. Research showed that caregivers of children with cerebral palsy who provided parental care to a child with chronic disabilities may affect both the physical health and the psychological well-being of the caregivers (Raina et al., 2005). Firstly, apart from studying the level of parental stress and psychological wellbeing in parents of children with physical disability, the physical health and the overall quality of life are to be further explored. Secondly, longitudinal study is recommended. In this way, the influence of the progressive nature of the disability, the personal growth of the children, and age of the parents and the parental caregiving on the level of parental stress can be further explored. A specific focus of parental stress can be studied in details in a
longitudinal study (Baxter, Cummins, & Yiolitis, 2000). Furthermore, since the health and well-being of the caregivers and children with disability mutually influence each other, studies on the relationship between children adjustment, parental adjustment and parent-child relationships (Barakat & Linney, 1992) are also suggested.

**Conclusion**

It is hoped that the present study would be one of those meaningful projects which contribute the well-being of people with disability and their caregivers. The empirical data from the present study would provide useful information for rehabilitation and social service providers on designing better support for PCPD that can pinpoint their stress and strain. The present study also provides evidences for raising the awareness of reducing stigma towards the parents of children with physical disability in our society. This is highly essential to the harmony and wellbeing of our society.

It should be emphasized that rehabilitation service is one of the aspects of the social welfare services offered by the Social Welfare Department. The service targets should include not only the persons with disabilities, but also their caregivers, parents and family members who play essential roles in the rehabilitation journey. More research on this area should be encouraged in the future; and the research findings are encouraged to be submitted to the Government to help promoting the quality of rehabilitation service in Hong Kong.
Reference


Behr, S. K., Murphy, D. L., & Summers, J. A. (1992). User's manual: Kansas Inventory of Parental Perceptions. Bureau of Heath Promotion, Department of Health, R.O.C. (Taiwan). Barthel Index. Retrieved online at http://www.bhp.doh.gov.tw/bhpnet/portal/file/ThemeDocFile/20070820110817/%E5%B7%B4%E6%B0%8F%E6%97%A5%E5%B8%B4%BB%E6%B4%BB%E5%8B%95%E9%87%8F%E8%A1%A8(The%20Barthel%20Index).pdf

stress and coping strategies between the parents of children with Duchenne muscular
Erickson, M., & Upshur, C. C. (1989). Caretaking burden and social support: comparison of
mothers of infants with and without disabilities. *American Journal on Mental
Retardation, 94*(3), 250-258.
NJ: Prentice-Hall.
Green, S. E. (2003). "What do you mean 'what's wrong with her?'": Stigma and the lives of
families of children with disabilities. *Social Science & Medicine, 57*, 1361-1374.
boys with Duchenne muscular dystrophy. *Developmental and Behavioral Pediatrics,
27*(6), 470-476.
risk and resistance factors. *Journal of Mental Health, 1*, 241-256.
with disabilities. *Exceptional Children, 70*(2), 231-244.
mental illness or intellectual disability. *Journal of Applied Research in Intellectual
Disabilities, 21*, 532-545.
Neff, K. D. (2003). The development and validation of a scale to measure
self-compassion.*Self and Identity, 2*, 223-250.


