

SUCCESS IN PARENTING CHILDREN WITH DEVELOPMENTAL DISABILITIES: SOME CHARACTERISTICS, ATTITUDES AND ADAPTIVE COPING SKILLS

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Introduction

The stress and coping difficulties of parents having children with developmental disabilities have been studied from both positive and negative points of view. Unfortunately, numerous studies tend to highlight the negative aspects of having a child with disability. These negative factors include: affecting the family's self-esteem, burdening the family's emotional resources and coping strategies, interrupting the normal routine of the family, and depriving personal growth opportunities (Beckman, 1983; Byrne and Cunningham, 1985; Ditchfield,

1992; Hadadian, 1994; Hanline, 1991; Mallow and Bechtel, 1999; McLinden, 1990; Margalit and Ankonina, 1991). All these negative impacts may lead parents to adopt maladaptive coping skills including feelings of guilt, pessimism, hostility, aggression and avoidance. Similarly, medical professionals also focus on how badly a child with disability would affect the family system and the stress thus created to the parents or caregivers. Parents and caregivers are identified as those who constantly need professional assistance and advice to raise their child, or even "curing" the problem once and for all (Browne and Bramston, 1998; Hanson

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and Hanline, 1990; Knussen and Sloper, 1992; Mallow and Bechtel, 1999; Singer and Powers, 1993, Yau and Li-Tsang, 1999). This paper reports a research that addresses the issue from a completely different point of view.

Although parents of children with developmental disabilities experience much stress, they also experience joys and gain their own strengths and skills in the care giving situation (Abbott and Meredith, 1986; McCallion and Toseland, 1993; Taanila *et al.*, 1999; Yau and Li-Tsang, 1999). These parents consider their children as having special needs, rather than problems. Successful, adaptive functioning families having children with developmental disabilities have not received sufficient attention. In their well-intentioned efforts to document areas of difficulty in families with children with developmental disabilities, researchers have sometimes neglected to describe successful family functioning within a different but not deviant family structure (Mallow and Bechtel, 1999; Kazak and Marvin, 1984). In fact, a growing body of knowledge supports that the presence of a family member with a disability may contribute to the cohesion of the family members, as well as contribute positively to the quality of life of individual members of the family (Summers *et al.*, 1989; Taanila *et al.*, 1999; Wikler *et al.*, 1981; Winzer, 1990). In some instances, where the parents are competent and supportive, siblings may also benefit from association with their brothers or sisters who are disabled because of increased opportunity to enact teaching, helping and caregiving roles (Stoneman and Brody, 1981). To meet the needs of families with children with developmental disabilities, it is important to study the "success cases" when searching for patterns in parental coping. If parental characteristics and family

attributes of success cases can be found, they then serve as a basis for positive adjustment and strength (Trute and Hauch, 1988).

There are very few studies investigating the characteristics of successful parents (Sanderson and Crawley, 1982; Yau and Li-Tsang, 1999). Sanderson and Crawley (1982) found that the majority of the successfully adapted parents in the United States were older and actively involved in church activity. Most of the mothers come from a conventional category e.g. they were brought up by a two-parent family and once they were married, they would stay at home to look after the children. Yau and Li-Tsang (1999) found some previous literature reporting the characteristics of adaptive functioning parents. These characteristics include high level of education, well-adjusted personality, better problem solving skills, positive view and realistic expectation of the child, less preoccupation with negative ideation. They also found that strong spousal relationship would enhance successful coping of the family. However, there is as yet little systematic study focusing on the positive adaptive skills of parents with children with developmental disabilities. A systematic study is essential to investigate the underlying attributes of these parents exhibiting a positive attitude and adaptive coping skills. However, the attitudes and coping mechanisms of parents are influenced by a lot of factors including social, cultural, economical and political background of the society in which they reside. This study, therefore, adopted a more qualitative approach to explore the attributes, beliefs and coping mechanisms of parents with developmental disabilities. This study also aims to explore how cultural and socioeconomic factors shape successful

management of family lives and to compare the results with previous research findings.

Methodology

The aim of this study was to observe and analyse the characteristics of the group of “successful” parents in their coping mechanisms, the attitudes and the help seeking behaviours in an Asian community. A qualitative methodology with an inductive approach was adopted to analyse and describe the coping skills of the parents. The analytic inductive approach of content analysis as described by Berg (1995) was adopted where existing dimensions or word units, emerging themes and categories were identified through reading the transcripts repeatedly. The researchers, who were experienced clinicians/professionals in the field of developmental disabilities, were involved in the content analysis process. Superimposed themes were formed by summarising and abstracting the categories coding of the interview data. Temporary hypotheses were formulated and then checked against the original transcripts to look for confirmation, qualification or disconfirmation of these hypotheses.

In this study, the “success of parenting children with developmental disabilities” refers to those parents who have positive attitudes towards their children with developmental disabilities. The selection criteria were:

1. Nominated by at least three professional staff, such as teachers, social workers, therapists or psychologists, who work closely with the informants;
2. Must demonstrate active participation

in parents support groups or other organised groups focusing on the provision and advocacy of services for the disabled;

3. Must be the natural parents of the children with disabilities.

It is due to the stringent selection criteria and the requirements for in-depth interview to review a lot of personal information that only ten parents were nominated and selected from the five parent organisations in the local community. These ten parents were either the chairmen or the executive committee members of these parent organisations. They were identified as parents with positive attitudes towards their children with developmental disabilities. Subject to their consent, the interview was scheduled between the professional and the parents. To ensure the trustworthiness of the information collected, a systematic procedure was carefully implemented. The study was conducted by an interviewer interviewing in depth, using a semi-structured format. The interviewer was a health care professional with extensive experiences working with families of disabled clients. Each interview lasted for approximately one to two hours. A series of open-ended questions were prepared for the semi-structured interview based on the literature and clinical experiences of the researchers. A set of questions was prepared for the interview (Appendix 1). All the interviews were audio taped and later transcribed. The key phrases were first obtained by frequency counts from the transcribed scripts. Then, these phrases were collected and formulated into several themes such as the social background, personal resources and the family relationships. Finally, a second reviewer would review the scripts again and re-evaluate the themes formulated by

the researcher to make sure it was coherent with the scripts.

Results

After transcribing the script, several superimposed themes were obtained and described as follows:

I. The Family

a. *The social background*

Nine mothers and one father aged between 35 to 60 years were selected for the interview. The age range of their children with disabilities was between 6 to 28 years, with five aged below five years. Only one child had no sibling while the other children either had a sister or a brother. The educational background of the informants were at least that of secondary school graduates. They did not report any major financial difficulties at the time of interview. Three informants reported that they had previously financial constraints when their children were young. Fifty percent of the informants were housewives whose major responsibilities were to look after the household and to take care of the children with disabilities. During the interview it also came to light that four of the mothers who stayed at home had decided to resign from their jobs after their children were born, so as to spend more time with their children. Four of them were working either full time or part time during the reporting period, while one had retired from his own business. These ten parents were either active members of parent support groups or actively involved in schools or church services. They were generally very pro-active and highly motivated.

b. *Family and marital relationships*

The informants themselves regarded themselves as being very family-focused and always put their family as their top priority in life. Most of them had good family support, either from the spouse, children or from the in-laws. The marital relationships were described as very good. The following notes extracted from the interview reports are good examples to illustrate this factor. All names mentioned in the following paragraphs are fictitious.

“Mrs. Sze reported that one day when she returned home after a long meeting at the parent organisation, of which she was the chairman, she was late preparing dinner for her husband and the children. She felt so guilty because she could not fulfill her role as the caregiver at home. Yet, when her husband returned home, he comforted her and said that he would fully support his wife to continue her services in the parent organisation. This impressed Mrs. Sze and she felt at ease for having such a supportive husband.”

“Mrs. Chan reported that her mother-in-law was the first person to comfort her when she knew that her granddaughter was a baby with Down’s syndrome. The old Mrs. Chan told her to be strong and that she would help to take care of this baby by giving her love and care.”

“Mrs. Wong, another interviewee reported that her mother-in-law who was very wealthy, openly requested her to leave her disabled son at home to be cared for by the maid while the whole family celebrated her birthday at the annual party. Mrs. Wong was very upset about her mother-in-law but she also reported that her husband gave her a lot of support and that they had been successful in convincing their parents

to accept their child with disability.”

The support from the spouse appeared to be a key factor in supporting the positive coping of these “successful” families. Only three informants commented that they had good support from the in-laws but the others reported a very negative picture. One of the informants reported that their in-laws sometimes would blame her for not training their children properly, like stopping them from screaming in public. The support from in-laws varies from family to family and it doesn’t seem to affect the parents’ success in rearing a child with disability.

c. Parent-child relationships

The ten childrens’ disability varied from a mild to a moderate degree. Two children were diagnosed with mental handicap with autistic features. These two children had severe speech delays, one child was only able to repeat what other people said and the other child only managed to produce monosyllables. The children of the study group consisted of six males and four females. Among the ten families interviewed, the mothers were the main caregivers of the children with disabilities. Four mothers decided to resign from their jobs after their children were born so as to spend more time with the children. The father usually played a less active role in the care of the disabled children.

The following examples were extracted from the interviews:

“Mrs. Lam, whose son was an autistic child, reported that she would never forget how her son started to look at her

for the first time five years after his birth. She still remembered the first word that her child produced at the age of 14 when he was calling her ‘mum’. Although her son was still dependent in daily living skills, she felt that any single step in her son’s improvement meant a lot to her and the whole family.”

“Mrs. Lee was so excited about her child being awarded as the most outstanding student in the year. She was very pleased with her child’s progress after attending the school. She was highly motivated to be involved in the training when her child showed significant improvement in the year.”

“It is me who brought this child into the world. I will not desert this child, no matter how difficult it is to take care of him/her.”

All parents commented that they would accept the children even though they had to meet with a lot of challenges and criticisms. They also treasured the improvement of their children, although it might be a trivial improvement like giving them a hug or having a good eye contact etc. They were very clear about their children’s strengths and weakness. More than half of the informants commented that they learnt a lot from their children and that they had a strong sense of achievement when their children had improved.

II. The coping mechanisms

a. Attitudes and social values

Here are some direct quotes from the informants on their value system:

"Before my son was born, I used to spend money on jewellery and beautiful clothes. Now I would spend more money on my child for his/her daily use or save it for future use."

"I was very career oriented and I used to be a senior executive in the company. Not until my second son was born with disability did I realise that there are more important things in life. I quit my job and I spent more time at home. I felt that the family should be my priority. My son has brought me the other aspects of my life that I treasure more."

"Both my husband and I are senior executives at work and we both received a higher education when we were young. We know that in order to help Yan, we have to provide the best environment for him to learn and develop his skills. We would not hesitate to spend money towards his training and education rather than just taking care of him. We have decided to go to the UK to seek a better training environment for my son, since we found that local services are not adequate".

Six out of the ten informants claimed to treasure family relationships more than the materialistic way of life after they gave birth to their children with disabilities. Although they viewed life in a very positive manner, at times they were worried about their children's future. Some commented that they would then focus more on present action while planning or preparing for a more distant future and others reported that they would save more money or search for a good residential placement for their children.

Very few of them put the blame on their partners, themselves or on 'God' for having a handicapped child. Less than half

of the informants had a religious background and there is no major difference in the coping mechanisms between those parents with a religious background and those without. Only two parents mentioned that it was God who gave them this child because God knew that they would be nice to the child. To them, raising a child with a disability became their mission.

b. Help seeking behaviours

The help seeking behaviours of the informants can well be illustrated from the following comments:

"Mrs. Cheung reported that her husband had paid more attention to family matters after her second son Joseph was born. She commented that her husband used to do very little housework in the past but then became very active in helping out. However, very few mentioned support from close friends, relatives or religious groups. They would rather seek help from other parents of children with disabilities."

"Mrs. Lee commented that when she was feeling distressed, she would contact some other parents of children with developmental disabilities. They sometimes communicated by having telephone discussions or having tea together to ventilate their feelings."

"Mrs. Wong said that she would seek help from professional staff whenever she felt upset about her child's behaviours. She would contact the school, social worker or during therapy sessions have a discussion with the therapists. She felt that the professionals could give her guidance and help."

Most parents would ventilate their stress and readily seek help from family members and parent support groups. Almost all parents reported that professional support and advice in the early stages were extremely helpful towards their acceptance of the disabled children. They also received reinforcement when their children had improved after parents' teaching or coaching. Thus, they felt that they are important and contributing towards the children's progress. Some would utilise the social resources to help in caring for their children like the application of respite care, home help services and community services.

Discussion

This research aims to study the characteristics of those parents exhibiting positive adaptive coping behaviours. By adopting an in-depth interview technique, the essential attributes leading to success and how parents perceive their life having a disabled child in the family were analysed. The essential attributes leading to "success" of parents were described as follows:

a. Personal resources

There are some unique characteristics of this group of Asian parents with positive coping behaviours that are similar to reports from Western families. They present themselves as being generally self-confident, positive, pro-active, sociable and outgoing. They have a good acceptance of their children in general and would readily speak up for them. They are usually very keen to explore resources and knowledge related to their children's

needs. They are active in advocacy and empowerment activities for children with disabilities. This in fact was reflected by a number of Western literature (Bregman, 1980; Friedrich *et al.*, 1985; Frey *et al.*, 1989; Hallaham and Kauffman, 1991; Yau and Li-Tsang, 1999; Winzer, 1990). In addition, this group of parents came from a higher educational background and this may be one of the reasons leading to positive coping behaviours as reported by Barber *et al.* (1988).

b. Family and marital relationships

All parents felt the importance of security and satisfaction with their spouse so as to develop a positive coping behaviour towards their disabled children. This observation is similar to the findings of Nihira *et al.* (1980) and Friedrich (1979). Most female interviewees reported that their husbands were very positive towards their disabled children. This research finding is similar to the study conducted by Frey *et al.* (1989) that spousal relationship is a strong factor in developing coping skills of parents with a child with disability.

c. Parent child relationships

In this study, there seemed to be little correlation between the degree of disabilities of the children and the level of acceptance of their parents. This was, in fact, different from the study conducted by Frey *et al.* (1989) who examined the relationship between parent and child characteristics and competencies and how these factors influence parent and child outcomes. They found that greater parental adjustment difficulties were associated with a linear increase in severity

of the child's communication impairment. There appears to be no significant difference on the level of acceptance between the disabled sons and daughters in this study.

The mothers were reported to be the main caregiver in the family. They were more active in the parent groups than fathers. Mr. Lam, the only father who agreed to participate in the interview, was already retired and thus had more time "spared" for the interview. Yet, he commented that although his son was only twenty years old, the main caregiving job was still done by his wife. This observation was similar to the study conducted by Bristol and Gallagher (1986) that the mother was traditionally assuming the role of primary caregiver.

d. Attitudes and values

This group of parents shows more positive attitudes towards life. In general, they value the present conditions rather than look back or worry about the future. They have a strong sense of responsibilities that they should teach their children and not just "take care" of them. Thus, this forms a very strong foundation of family education. They believe that they should actively seek social support, instead of waiting for help to come. Even though their participation in those support groups may not always benefit their children directly, they gain satisfaction, experience and social support to enhance their own coping and adjustment. They also actively search for information and resources for their children and seek professional help where necessary. When they are in distress, they would also seek help from other parents in the support group for advice and sharing.

In return, they are willing to share their experiences and offer their advice to other parents when needed. Ultimately, they find satisfaction and a sense of achievement from these parent organisations, thus reinforcing their positive attitudes and coping mechanisms.

In sum, a secure and strong marital relationship with mutual support and concern between spouses would definitely affect the positive coping behaviours of the family. A strong feeling of personal reward associated with parenting and good communication with family members also contributes to the positive coping behaviours of the parents. Lastly, active participation and sharing in social support groups would also enhance the positive coping behaviours of parents.

Limitations of the Study

The limitation of this study is the small number of samples collected for analysis and that the themes obtained from the interview cannot be generalised to all parents with children with disabilities. It is also not the intention of this study to substantiate a hypothesis but to look for the common characteristics of parents who are more "successful" in parenting their children and how they develop positive attitudes towards people with developmental disabilities. The study was conducted in an Asian community and the difference in culture and value system may have influences on the coping mechanisms of parents with children with disabilities. However, it would be interesting to have a cross cultural study on a similar topic in the future.

Summary

This study aims to find the coping mechanisms of parents having children with disabilities. Ten parents were identified as having positive coping behaviours. A semi-structured interview was conducted with them and the discussion was transcribed. A qualitative analysis was conducted and several themes were obtained from the interview. It was found that parents with positive adaptive behaviours have a relatively high education level. They have a stable family structure with little financial difficulties. They have a simple family structure consisting of both parents and at least one sibling living with the child with disabilities. These parents are usually outgoing, confident and efficient in time management. It was also found that strong spousal relationships appear to be the main factor attributing success in coping. As well as the family structure, these parents have open attitudes and are highly motivated to search for a local network and social support for their children. They treasured more the education of their children and value their progress. Although they have worries about the future of their children, they would try to resolve problems in a realistic manner. They would seek help and advice from the spouse and close family members. At times, they would also seek help from other parents in the support group and in return, they would offer their advice and help to those who needed it. They also gain satisfaction from helping relationships, thus reinforcing them to continue their active participation in the parent groups and sustain their positive attitudes and coping mechanisms towards their children.

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Appendix 1

The questions for the scheduled interview are:

1. How do you take care of your child? Tell me something about your child's present condition.
2. How does your child affect your life and your marital relationship? List some of the difficulties in taking care of your child.
3. How do you see your life change comparing before and after the child's birth?
4. How do you overcome these barriers?
5. When is the turning point? How does this change which occurs turn disappointment to a more positive outlook?
6. What makes you stand up and speak up instead of withdrawing?
7. How does your child affect your self-confidence, self-esteem and life view?
8. How do you manage your time?
9. Does your child impose an extra stress on your daily life and how do you manage this stress?
10. How do you see your child's future and your future?
11. At present, what kind of supportive system do you have? Is it enough?
12. How can you help yourself to feel more positive?
13. What is your husband's perception on having a disabled child?
14. If you did not have a child with disability, how much different do you think your life would be?
15. What makes you so proactive? What makes you so actively involved in the parent support group?
16. What do you think causes you to be so positive over the years?
17. What are your unique attributes or characteristics that you think contribute to your successful adjustment and adaptation?
18. How satisfying is your life at present?

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