

Raising Kids with Down Syndrome: Experiences of Selected Parents in the Philippines

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Abstract: Down syndrome (DS) is defined as human beings with extremely low or depleted intellectual capacity due to chromosomal abnormalities. Having children with Down syndrome gives challenges in parenting; they can have stress, anxiety, depression and other psychological problems (Weiss, Sullivan & Diamond, 2013). In view of this, the study investigated the parents' (1) appraisal system; (2) problems and challenges; (3) coping strategies/mechanisms; (4) its impact to their personal lives, family lives, and social lives. Qualitative design was utilized through in-depth semi-structured interview with 6 parents (5 mothers and 1 father). Data gathered were examined using thematic analysis based on the pre-set criteria by the Transactional Model of Stress and Coping by Lazarus & Cohen (1977). Results suggested that parents' appraisal of their familial situation can be understood through various perspectives in the cognitive, affective, and behavioral domains. Most of the problem that parents encountered centered on general family issues; hence, having a child with DS does not aggravate familial burden. Specific problems brought by the condition are usually coped through the use of avoidance, denial, social support and religiosity. These coping mechanisms however can only be dismissed effective only with the help of other family members, friends and love ones. What plays a major role in this particular parental experience is the quality of their appraisal system and coping mechanism. Educated and informed considerations relative to their child's condition as well as positive coping strategies provide protective factors to their overall parenting.

Keywords: Parenting, Down syndrome, Transactional Model of Stress & Coping

1. Introduction

Having children with Down syndrome (DS) gives a different challenge in parenting, challenge such as facing and coping with different problems. Parents can have stress, anxiety, depression and other psychological problems (Weiss, Sullivan & Diamond, 2013). These problems may come from different sources: one of these depends on the age of the child having from Down syndrome (Fidler, Hodapp & Dykens 2010) and the time for the leisure and other social activities of the parents (Wayne and Krishnagiri, 2016). A number of previous studies already demonstrated other coping mechanism that has been used; girls are more likely to use social support than males (Sullivan, 2012); fathers have more positive outlook towards life than mothers (Rodrigue, Morgan & Geffken, 2012); other parents used avoidance coping style (Cheng and Tang, 2015) and some of them were going to initial stage of denial, disbelief, and even grief.

Problems experienced by parents of children with DS may come from different sources. Fidler, Hodapp and Dykens (2010) tried to know the stress experienced by families of young children with DS. The results showed that families of children with Down syndrome experienced significantly less pessimism than the any other disorder. The strongest predictor of parent and family problem in DS was the age of the child. Scott, Atkinson, Minton and Bowman (2006) stated also that the distress level of parents who had infants with DS gives a greater depression for the parents. Although, Slopen, Knussen, Turner, & Cunningham (2001) reported that for fathers, child characteristics were not related to outcome. The marital relationship was an important factor to the family that acted as stressors. Lam and Mackenzie (2012) identified seven themes about the problems that parents are going through while having a child

with DS. These are "unexpected birth of an abnormal child, acceptance of the child, special needs of the child, worry about the future, knowledge deficit, effect on the marital relationship, and social restrictions. The types of stressors changed over time according to the child's age, and coping strategies varied accordingly".

Cheng and Tang (2005) described that parents of children with DS reported the most frequent use of avoidance coping style. In their study, parents reported a higher level of psychological distress, were less optimistic, felt less self-efficacious, and engaged in more frequent use of self-reliance coping style. Mothers reported a higher level of distress but lower levels of optimism and self-mastery. Lam and Mackenzie (2012) affirmed that the common coping strategy that parents using were avoidance, self-reliance, and seeking social support. Spangerberg & Theron (2009) on the other hand, argued that mothers of children with DS used a "social support-seeking coping strategy significantly more than fathers did". While on the study of Rodrigue, Morgan and Geffken (2012), fathers of children with DS reported more frequent use of wish-fulfilling fantasy and information seeking as coping strategies as well as more financial impact and disruption of family activities than did fathers of developmentally normal children. In addition, Cohen (2004) found that mothers of DS children go through the initial stage of denial, disbelief, and grief upon learning that their newborn infant is not normal.

In light of the objectives of this study, it sought to answer the following questions: (1) how do parents appraised their child's condition? (2) What are the problems do the parents experience with their children who have Down syndrome? (3) What are the coping strategies/mechanisms parents put into practice to cope with their problem? (4) How do these problems change their lives in terms of the following

domains: personal life, family life and social life? This study was guided by the classic theory of *Transactional Model of Stress and Coping* by Lazarus and Cohen (1977), which is a framework for evaluating the processes of coping with stressful events. Stressful experiences are construed as person-environment transactions. These transactions depend on the impact of the external stressor. This is mediated by firstly the person's appraisal of the stressor and secondly on the social and cultural resources at his or her disposal.

2. Methodology

Research Design

Descriptive Qualitative Design guided this study up to its fruition. Central to this is the examination of human experiences through self-report and detailed descriptions of the phenomenological experiences of the Parents of the children with Down syndrome.

Participants

This study covered at 6 individuals: 5 mothers and 1 father. They were selected from San Jose City, Guimba, and Talavera, Nueva Ecija, respectively.

Instrumentation

Unstructured Interview Schedule was devised as a guide in drawing out information from the respondents covering the study objectives.

Data Gathering Procedures

Respondents were oriented about the study objectives and procedures followed by solicitation of consent and rapport building. Data gathering was done in a total of 3-5 months with 3 staggered hours per interview per subject per week. Interview questioning was generally "free flowing". Tokens of appreciation were provided to each parent as a gesture of gratitude and termination.

Data Analysis

The study used thematic analysis in understanding the meaning of the descriptions and narrations of the respondents. The goal of the analysis is to learn something about the participants' psychological world. Meaning is central, and the aim was to try to understand the content and complexity of those meanings rather than measuring their frequency.

3. Results

Respondent No. 1: Annie

Primary Appraisal: (a) *Cognitive*. Annie questioned herself deliriously why and how she got a child 'like that'. At first, she could not fathom the idea of taking care of a child with DS. (b) *Affective*. She admitted being sad and unable to accept the fact that her child has DS. (c) *Behavioral*. She was unable to do anything out of shock and was just "standing still" while trying to digest and process how she could accept the fact that her child has DS. **Secondary Appraisal.** Annie utilized the connections she has with her friends and workmates to reach out emotional support and spiritual enlightenment about her child with DS.

Problems Experienced. (a) *Personal*. Annie experienced very minimal personal problems in relation to her child's condition because she was not the one who took care of her child for 8 years and would just rather visit one to two times per month. She admitted however that she was still deeply sad about her child's condition. (b) *Family*. Annie's parents were very helpful in her difficulty accepting her child's condition. However, she found her husband's reaction rather disheartening because he was ignoring their child deliberately for quite some time until he finally accepted it. Similarly, a very rejecting attitude from majority of their relatives made it burdensome because they questioned her for having a child with DS. (c) *Social*. Unfounded, unjustified and demoralizing judgments from people around them made it the most challenging for her parenting.

Coping Mechanisms: (a) *Problem-focused coping*. Annie confessed that the main reason she worked in a long distance workplace was to escape and avoid her parental obligations to care of her child with DS. (b) *Emotion-focused coping*. Since day one, Annie denied to herself that she has a child with DS; she can't accept the truth so she left her child in the care of her parents.

Changes: (a) *Personal*. Annie argued that nothing's really changed in her personal life even after she knew that her child had Down syndrome. (b) *Family*. Since she was unable to take care of her now 10 years old child, she cannot ascertain what specific changes have been caused by this experienced; however, she argued that her husband's treatment with their child only changed very minimally – indicating inability to fully accept their child's condition. (c) *Social*. Annie's social life did not change significantly as brought by her child's condition.

Respondent No. 2: Bianca

Primary Appraisal: (a) *Cognitive*. Bianca's knowledge of the signs and symptoms of DS enabled her to identify the said condition to her child. This however did not serve as a buffer against her thoughts of questioning herself for having such a child, even denying to herself such fact even though it was already plain obvious to her. (b) *Affective*. This self-denial caused her to become down and momentarily depressed for quite some time. (c) *Behavioral*. As a result, she was often found crying by her family members. She mentioned that crying even on her own for multiple occasions helped her to manage the situation which eventually empowered her to treat her child as normal like other kids. **Secondary Appraisal.** Bianca conditioned herself of the utmost importance of motherhood which tremendously helped her in appraising her situation as a parent. Similarly, her deep and strong faith and spirituality enabled her to solidify her acceptance of their situation.

Problems: (a) *Personal*. Her struggles to fully accept her child's situation in spite of her knowledge about the condition was the most burdensome to Bianca. (b) *Family*. As a very devoted mother, she found it very exhausting the explaining she had to do to her other children to make them understand the condition of their sibling. She makes her daughter and two sons to understand that majority of her time were needed by her child with DS. This made the

siblings inadvertently jealous; this is for was the most challenging of all. (c) *Social*. Insensitive comments, like blaming her for having a child with DS due to being sinful, from the people around them made it very difficult for her. However, support from her family and friends made it more bearable for her.

Coping Mechanisms: (a) *Problem-focused coping*. Bianca stopped from working to fully focus and attend to her child's special needs. (b) *Emotion-focused coping*. As mentioned, she coped her situation by crying – even excessively, to lessen her sadness. In addition, cling to her faith helped her a lot in accepting the condition of her child.

Changes: (a) *Personal*. Giving up her career to become a full time mother is the most significant change in her personal life. (b) *Family*. As a consequence, her husband became even more hardworking to make both ends meet. The sibling relationships were also observed to become closer and deeper in spite of the occasional jealousy and envy that arise. (c) *Social*. Since Bianca became much focused to her children, she didn't have any time to go out and enrich her social life, though she argued that she was happy with her situation.

Respondent No. 3: Carla

Primary Appraisal: (a) *Cognitive*. Carla did not have any knowledge about the condition of her child and only realized it when they went to the doctor and her child was already 3 years old. Upon learning about the condition, she straightaway became concerned of her child's future and the treatment the society might do to her. (b) *Affective*. She said that it was very heartbreaking for her when she found out that her child has DS. She felt very sad as it was all too painful for her because she took the blame on herself. (c) *Behavioral*. As a result, she sulked herself for three days in her room, she recounted.

Secondary Appraisal: Overcoming her reactions, she considered her husband as one of the persons that kept her fighting from the sadness that she felt when she found out the condition of her child. Her husband helped her to accept the situation. Her sisters, brothers and uncles altogether helped her to take care of her child which also contributed to her acceptance of her child's condition.

Problems: (a) *Personal*. Carla argued that she didn't have any problem or issues regarding her personal life because her sister and other relatives took care of her child and she kept her work while parenting her children. (b) *Family*. Similarly, Carla did not have any significant problem in her family with regards to her parenting of a child with DS. She explained that this is largely due to their closely-knitted family system. (c) *Social*. Her social life did not change significantly either. However, she found it most annoying when other people insensitively laughed at her child.

Coping Mechanisms: (a) *Problem-focused coping*. Carla's brooding for 3 days served as a distraction for her to overcome her problem about her child with DS. Most meaningfully, their decision as husband and wife to have another baby helped both of them to cope with their situation

and to strive to become even better parents. (b) *Emotion-focused coping*. As a response to their marital decision to extend their family, they agreed to educate themselves about DS and thus became more prepared if ever their second child will have the same condition. Hence, they both because an ardent advocate of good parenting to children with special needs.

Changes: (a) *Personal*. To Carla, becoming a better parent was the most significant personal change for her. (b) *Family*. Extending their family by having another baby in spite of their fear of their eldest' present condition was a challenging venture for her. (c) *Social*. Carla did not have any significant change in her social life in terms of her parenting a child with DS.

Respondent No. 4: Diana

Primary Appraisal: (a) *Cognitive*. Diana did not have any idea that her child has DS; it was her husband and sister-in-law who explained things to her and convinced her to see a doctor. She did not agree at first because she cannot accept the fact that her child was a so-called "mongoloid"; it was very hard for her. (b) *Affective*. Diana confessed that it was embarrassing for her to have a child with this condition. She also said that it was hard for her to accept the fact that her child has DS for quite a long time. (c) *Behavioral*. As a result, she always evaded questions pertinent to her child's condition and refused to educate herself about it.

Secondary Appraisal: Diana required much effort to digest and fully realized their child's condition. It was her husband who helped her get through this but it took them considerable amount of time to finally convince her of their child's situation. Having many people around including her in-laws helped her to take care of her child to the fullest. As a result, she didn't have any hard time regarding the situation of her child.

Problems: (a) *Personal*. Balancing her duties as a mother to all her children was a big challenge for her and an issue for her other kids. She also confessed that she still feel embarrassed at times about her child's condition. (b) *Family*. Making her other children fully understand what it takes to take care of their sibling with special needs is the most perplexing task for her. (c) *Social*. Dealing with other people who mistreat her child is the most glaring problematic experience she has for her child with DS; however, she was happy to see that her other children protected their sibling when somebody discriminates him.

Coping Mechanisms: (a) *Problem-focused coping*. Diana tried educating herself about DS though unfortunately to no avail. (b) *Emotion-focused coping*. She refused to fully embrace her child's condition; she still occasionally feels embarrassed about her child. She admitted to still try to deny that her child have that condition to lessen the negative feelings she have.

Changes: (a) *Personal*. Diana did not mention any personal problem in relation to her parenting of a child with DS. However, her outright admission of shame and inability to fully accept her child's condition can be considered a major

personal problem unbeknownst to her – of which she constantly denies, too. (b) *Family*. Giving undivided attention with her seven children was not an easy thing to do, especially if one of them had DS. She gave more time and attention to her youngest which made her other children jealous. (c) *Social*. Her socialization was affected and limited by her child's condition. Nevertheless, despite of all the negative feelings she has, she still has time to visit friends and show them her child.

Respondent No. 5: Emily

Primary Appraisal: (a) *Cognitive*. Emily found out that her child has DS when he was 11 months old. She noticed a change in her son when he was 7 months but she didn't want to accept it which hindered her to see a doctor until her husband convinced her. When the condition was confirmed, she was confused as she cannot fathom parenting to a child with DS, including how such condition developed and how she, as a mother, could move forward for their son. (b) *Affective*. Even though she saw the signs even before it was confirmed, Emily was shocked to her guts because she could believe that she had bear a child with DS. This caused her to become depressed which took her more than a year to recover. (c) *Behavioral*. She brooded for more than a year until she finally accepted her child's condition. At that time, she decided to join in the Down syndrome Organization of the Philippines where she participated actively in various orientations, seminars and free check-up for her child.

Secondary Appraisal: Emily's husband is the major source of her support in her struggle to fully understand the situation of her child. Similarly, self-help group like the aforementioned helped her significantly where she felt becoming a part of something bigger than herself both as a person and a mother.

Problems: (a) *Personal*. As a career woman helping her husband make both ends meet, Emily found limited time to take care of their children especially her son with DS. This, for her, is very heartbreaking. (b) *Family*. Struggling to keep their finances in balance, especially with their son's condition, Emily's husband decided to work as an OFW while she kept her job to help him. This was most troubling for them as a family. On the other hand, her other children didn't seem to have any issue regarding the situation of their brother and were even concerned of him. (c) *Social*. Emily mentioned that she didn't have any problem to other people in relation to her child's condition. She was even thankful to her friends and relatives who aided them financially when their son was hospitalized.

Coping Mechanisms: (a) *Problem-focused coping*. Joining the professional organization for the people with DS helped them a lot especially because of some free medical check-ups for their child, on top of the knowledge they gained to further understand their child's condition. (b) *Emotion-focused coping*. Emily shared that because of the seminars brought to them by the Down syndrome of the Philippines, her sadness and depression were lessened. She came to realized herself that she was even lucky because there were cases that were more severe than her son's condition.

Changes: (a) *Personal*. Balancing her time as a mother and as career woman was most taxing for her. (b) *Family*. Becoming a sole present parent for their 3 children – of which one has a DS, is most challenging to her. However, since her husband went to Thailand to work, she noticed that her other 2 children grew more matured, caring, and protective of their youngest of whom with DS. (c) *Social*. Emily's social life was even improved after she gave birth to her child with DS due to her active involvement to the mentioned National Organization. She never felt embarrassed because of and for her child.

Respondent No. 6: Francis

Primary Appraisal: (a) *Cognitive*. To Francis, he and his wife did everything to make the pregnancy the best possible it could be, especially after 2 miscarriage prior to their youngest. When he found out that his child has DS, he got very confused because for him, they did not misstep a single procedure. He cannot imagine the condition of their child. As a result, he questioned God for the fate He has given them. (b) *Affective*. Francis never felt such frustration before – especially after 2 miscarriages and when they finally got pregnant, the child was "abnormal". (c) *Behavioral*. He admitted that at first, he can't accept his child and he can't even look at his child. When he was informed by the doctor that his child needed to undergo various medical procedures, he finally realized that he was needed by his daughter. He toughened up himself and set aside his biases and frustrations and asked his eldest to help in their crusade to help their youngest.

Secondary Appraisal: Though Francis questioned God, his trust and faith in Him did not falter and decided to even strengthen it, most especially at times like that. He began realizing that his child was a big blessing and not a punishment for him.

Problems: (a) *Personal*. Due to his child's condition, he will quit his job as a seaman to focus more on his family. Even though he didn't lose sight of what's truly important for him, he felt that he let go lots of opportunities by leaving his work. (b) *Family*. Francis was sad and challenged by the fact that his other daughter have been jealous with her brother – of whom with DS. In addition, some of their relatives were ashamed of his child for having a DS, he sensed. He didn't know how to talk to them and explain his child's condition. (c) *Social*. Francis said that nothing was really bothering him socially speaking. He argued that even if someone said negative to his child, he just ignore them because if he reacts, he will be just like them, he explained. He affirmed that he never felt ashamed of having a child with Down syndrome. He even took his child anywhere he goes as much as possible.

Coping Mechanisms: (a) *Problem-focused coping*. His avoidance to see his child and questioning God for such child, though needlessly negative, propelled him to become more proactive in his quest to understand and even advocate for children with DS. (b) *Emotion-focused coping*. Praying was the only solution that Francis had. He said he prayed for strength. He also said that, God will never give him a problem that he cannot face. Though at first he's in denial on

the condition of his child, he still managed to accept his child fate lighter than the first time.

Changes: (a) *Personal*. As brought by the combined effect of previous miscarriages and having a child with DS, he became more ardent and proactive both as a father and businessman; their business excelled and their life has been lighter since their child with DS came to them. (b) *Family*. Francis stressed that his family has never been as happy since they had their child with DS. Their spirituality was also strengthened as a family. (c) *Social*. Because of their utmost support to their child with DS, Francis and his family's socialization were even more improved because they want to inculcate to him the value of having a social life and they do their best to help him develop his social skills.

4. Discussions

Unanimous of the respondents' initial cognitive reaction to their child's condition was denial and frustrations on which they have negative to no understanding of the condition. Much can be expected when a family learns that its child has a disability, initial reactions usually are shock and disbelief (Shapiro, 2012). Some others even suffered symptoms of depression and social anxiety because no matter how hard they try to deny their child's situation, they cannot run away from their responsibilities as parents. Similar concerns were also observed in some studies in the western society (Spangenberg & Theron, 2009).

Having a supportive family and friends served as rather an effective buffer against the unpreparedness and lack of sufficient knowledge among the respondents. Our culture as being family oriented served its purpose well: they look at the condition of their child as negative (shameful, burdensome, and even sort of punishment) but with the help and support from their family members, they faced their problems lighter and eventually realized how blessed they had become because of it. In addition, relatives generally have positive attitudes towards the child with disability and display deep concern and pity towards the family (Shapiro, 2012) also played a crucial role in their parental experiences.

Drawing from the Transactional theory, a situation could be a problem or stressful for the parents if their appraisal were pessimistic. Undisputed among the respondents, their primary appraisals were all negative due to preexisting biases to, and lack of knowledge on, DS. However, their secondary appraisal, which is concerned on how they looked for options that could lessen their thoughts, feelings or negative behaviors due to having a child with DS, were rather positive and more helpful. The family and friends of the parents were big help for them. The support and help they got from their significant others helped them to take the situation of their child lighter than the first time they ever thought it would be. This was observed to be helpful because all the family members felt obligated to direct their attention and effort to the child in need; they adjust their lives and priorities to meet the child's needs.

The whole family was affected when they had one member with disability or disorder. Family with a younger member who had the disorder was the most affected. All other

respondents have other children. Giving enough attention to their child with Down syndrome was the most common source of problems in the family. Another source based on the literature was the age of the child who had DS. As Scott, Atkinson, Minton and Bowman (2006) stated, the "distress level of parents who had infants with Down syndrome gives a greater depression for the parents". It was true that before when the children of the respondents were young and having the said condition it was harder for them to accept. But when the child grew older, the stress they had were lessened and the condition of their child were not given more importance than the first time they knew about the condition. In addition, Filipino families view children with mental handicaps as bringers of luck; others think that they are being punished if they have a disabled member (Carandang, 2004); in terms of the respondents, both rung true among them.

On the other hand, most of the respondents used avoidance to escape from the situation brought about by their child's condition in order to lessen their problems or stress, similar to other studies (Cheng & Tang, 2005). This thus can be dismissed as 'problem-focused coping' – it is the strategy that people applied in order to deal with the cause of their problem (Weiten, Wayne & Lloyd, 2016); it also involves attempts to do something constructive about the stressful conditions that are harming, threatening or challenge an individual. Further, all the respondents tried to reinterpret their situation through denial (Cohen, 2004) and wishful thinking to alleviate negative emotions brought by their misconception about their child's condition. This, thus are considered to be "emotion-focused coping". This coping style occurs when the person modifies the way they think (Weiten, et, al.).

Allotting sufficient time to their family, especially the ones with special needs, was the biggest challenges that happened to, and changes that faced the parents of children with Down syndrome. On top of this, balancing attention and affection to all their children was also taxing and perplexing for them. However, the undying support and understanding of their spouses served as the biggest buffer to their problems in parenting their children with DS. This becomes more potent when families and friends also become supportive in most of the facets of their parenting. Close-knit family traditions thus tend to make parenting children with DS more bearable, even enjoyable depending on the quality of their appraisal and effectiveness of their coping mechanisms and strategies. Similarly, parents' social life was not negatively affected even though their responsibilities and obligation to their children with Down syndrome was more pronounced. In fact, this very parental experience can be an opportunity to improve the entire family's socialization by engaging themselves to bigger grounds like participating in self-help groups and organization serving civic causes.

5. Conclusions

As suggested by the data gathered from the parents of children with Down syndrome, the following conclusions are hereby made:

- 1) Parenting children with DS presents unique adjustments and challenges that can either be lighten up or burdened

- by the quality of their appraisal system and effectiveness of their coping mechanisms and strategies.
- 2) Proactive appraisal systems significantly aids in the quality of parenting children with DS. Specifically, positive primary appraisal can be done by suspending one's biases regarding the said condition and educating oneself thereafter as secondary appraisal seem to be effective.
 - 3) Effective coping mechanisms in parenting children with DS seem to constitute to strengthening social support system and committing oneself to greater civic causes.
 - 4) Jealousies, sibling rivalry, and balancing attention are the major problems associated with parenting children with DS.

6. Recommendations

Based on the conclusions of the study, the following recommendations were here made:

- 1) For the parents of children with DS, suspending one's biases and educating themselves about the condition can be an effective preparatory and enduring parental procedure. Joining self-help groups and national organizations committed to civic causes for Down syndrome is also highly recommended.
- 2) For the future researchers, expanding the socio-demographic characteristics of the parents could significantly improve applicability of the data gathered. This includes increasing the number of respondents, gender (balancing the number of fathers and mothers), regions, and length of parenting experience. Similarly, more sophisticated qualitative approaches, like Consensual Qualitative Research, is also recommended to further investigate the parents' appraisal system and coping mechanisms.

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