

THE LIVED EXPERIENCES OF URBAN POOR MOTHERS WITH CHILDREN WITH CEREBRAL PALSY

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INTRODUCTION

Parenting can be difficult. Parenting children with severe to profound disabilities can be more challenging and stressful (Ahmad & Khanam, 2016). Mothers of children with severe disability experience higher levels of chronic stress than mothers who have children without disability (Geikinia & Martinsone, 2015).

Cerebral Palsy is a chronic neurological disorder caused by a non-progressive brain injury or malformation that occurs while the child's brain is under development and it primarily affects body movement and muscle coordination (Hallahan, Kauffman, & Pullen, 2012). As in any disability, the degree of severity can be mild, moderate, severe or profound (Smith, 2010).

Mothers play a crucial role in the rehabilitation of their children (Ahmad & Khanam, 2016; Geikinia & Martinsone, 2015). Given this, the researcher has decided to conduct this research in order to develop counseling and other psychosocial programs for mothers who have children with disabilities.

This research identifies parenting practices, stressors/concerns, and coping mechanisms of mothers who have children with cerebral palsy.

This research will benefit mothers who have children with cerebral palsy and other disabilities. It will help them reduce stress levels, identify their concerns and appropriate programs and services can be created for them. It benefits institutions that cater to children with cerebral palsy as psychosocial interventions can be formulated to address mental health and wellness issues. It further benefits schools that cater to this population as parenting programs can be created by the guidance counselors.

SCOPE AND DELIMITATION

This research is part of a program given for Philippine Cerebral Palsy, Inc(PCPI). The Executive Director of the PCPI requested the researcher and her graduate students to develop a program for their clientele. This research serves as a part of the needs assessment for a parenting support program. The term, *lived experiences* is used as this research details first-hand accounts and impressions of the mothers who have children with cerebral palsy who are considered as a minority group compared to the mainstream population. This research discusses parenting practices, stressors and concerns, and coping mechanisms used by the mothers. The PCPI invited both parents to come participate in the psycho-social support program but only mothers replied. They said that the fathers are busy earning a living.

Initially, the researcher wanted to identify levels of stress, coping mechanism and resilience among the mothers. However, during the initial rapport-building activities that the researcher had with her students, it was observed that some of the mothers do not have the comprehension skills needed to respond to the scale questions. Based on the files, some of the participants only completed elementary education. This phenomenon would affect validity. Given this, the researcher opted to gather data qualitatively through a focus group discussion.

METHODOLOGY

This research is qualitative in nature. Initially, the researcher wanted . The term, *lived experience* is used to describe first-hand accounts and impressions of living as a member of a minority group (Ezzy,1998) . It follows the narrative inquiry approach, which emphasizes the understanding, remembering and retelling of narratives (Clandinin & Connelly, 2000; Creswell, 2009; Denzin & Lincoln, 2011; Hatch, 2002), it described the participants' lived experience as mothers with children with cerebral palsy. However, beyond exploring their life stories, its aim was to discover essential themes evident among these narratives and gain lessons to empower mothers who have children with cerebral palsy.

The researcher obtained data through focus group discussion held on March 25, 2017. The researcher wrote down the responses of the participants as they spoke. Before the session ended, the researcher read the responses that each participant made as a springboard to the synthesis of the discussion and for clarification. After this, the narratives were subjected to thematic analysis where themes and patterns of data were obtained (Boyatzis,1998). It involved repeated reading of the data to identify meanings and patterns, production of initial coded, sorting of codes into themes into a coherent and internally consistent account with accompanying narrative; and final analysis (Braun & Clarke, 2006). These themes and patterns were, later on, reconfirmed and explored for discussion in the summary, conclusion and recommendation of the study.

Research Locale

The research was conducted in Philippine Cerebral Palsy, Inc. (PCPI) Barangay Sacred Heart Makati City. This institution caters to financially disadvantaged persons who have cerebral palsy. It gives occupational and physical therapy services at a minimum cost. Volunteers give psycho-educational services to their clients.

The researcher has been one of their partners since 2009. Through the years, she has sent graduate practicum students in Special Education and Guidance to assist them. For this semester, PCPI has requested for a counseling program for their clients with cerebral palsy and their families. This research partially forms as a needs assessment for the parents. The results of this study, are furnished to the PCPI.

Research Participants

There were 13 mothers who have children with cerebral palsy with age range from 10 to 16 years old. All of the participants are full-time housewives. All of their children are immobile and have to be carried or placed in a wheelchair. None of their children could navigate a wheelchair because of their condition. Their children either have ataxic, spastic or mixed cerebral palsy. Their children are either non-verbal or have limited language. All of their children receive physical and occupational therapy at PCPI. Their spouses either work as tricycle drivers, jeepney drivers, construction workers or work odd jobs to make a living.

The participants were given code names of Minerva, Bea, MJ, Evelyn, Dina, Cecilia, Dang, Beth, Tess, Nora, Nylyn, Mhel, and Josie. All of them have children with cerebral palsy with ages 5 to 20 years old. Bea's 15-year old daughter has both cerebral palsy and retinal detachment, causing her blindness. Nora has another child who has down syndrome. Except for Josie who is separated, all the mothers are married.

Initially, the researcher attempted to administer the Parental Stress Scale, the Parent Resiliency Scale and the Coping Mechanisms test. However, the reading skills of some of the participants are not sufficient to respond to the items of the tests. Given this, the researcher opted to ask open-ended questions to gather data. During the course of the focus group discussion, the researcher observed that some of the participants gave short answers and requested to re-tell or elaborate some questions. All of the participants are in middle adulthood with age range of 35 to 50 based on the records of the PCPI.

RESULTS AND DISCUSSION

Parenting Practices of Mothers with Children with Cerebral Palsy

Initially, the researcher wanted to identify parenting styles on whether the participants were authoritarian, authoritative, permissive or indulgent. Parenting styles is said to affect children's engagement in activities and contributes to their development and acquisition of skills needed to overcome their disabilities (Kim & Mahoney, 2004). In order to identify parenting styles, the researcher initially asked, how they are parenting their children (*Paano po kayo gumaganap bilang magulang sa mga anak ninyo?*) and how they discipline their children (*Paano po ninyo dinidisciplina ang inyong anak?*). However, the researcher could only extract themes on the roles that they function at home and not on discipline patterns as most of the participants could not elaborate on their responses on discipline. They just say that they spank the children or shout at them. There is no clear indication of a pattern of discipline. Given this, the researcher focused on parenting practices.

The participants operationalize parenting as household management. Most of them mentioned chores that they do every day. The mothers had to perform chores at home as they do not have money to pay for household help. Other tasks involved settling disputes, budgeting and discipline. Table 1 shows the responses:

Table 1. Household Management

| Theme | Code | Data Extract |
|----------------------|---|---|
| Household management | Helps the child with cerebral palsy in activities of daily living | <i>Pinagluluto ko siya, pinapakain, pinapaliguan, dinadamitan at nililinis.</i> I cook, feed, bathe, clothe and cleanse them. (Minerva, Evelyn, Dina, Beth, Cecilia) |
| | Settles disputes among siblings | <i>Pinapaliwanag ko sa mga nagseselos na kapatid na pantay ang pagtrato ko sa kanila para di sila magalit</i> I explain to my other children that I treat them fairly so that they won't get angry (Mhel) |
| | Budgets for needs, therapy, education | <i>Pinagkakasya ko ang pera para sa therapy, gastusin at pag-aaral</i> I budget the money for therapy, expenses and education. (MJ, Tess) |
| | Disciplines children | <i>Dinidisciplina ko ang mga anak ko at pinaparusahan ko kung nagkamali sila.</i> I discipline my children and punish them when they commit mistakes. (Nora, Dina) |

Performing household chores and assisting the child with cerebral palsy was the top answer on their parenting practices. The researcher noticed that the mothers seemed to be very committed to their parental obligations towards their children. Mothers who have low socio-economic status are more concerned with doing household obligations such as domestic chores as they could not hire household helpers (Button, Pianta & Marvin, 2001). For many adults, parenting roles are coordinated with other roles in life (Santrock, 2013). However, in the case of these mothers, their life has been focused on fulfilling day to day chores needed by their families. In fact, Minerva and Cecilia verbalized that the daily grind causes them much stress as they have a long list of activities to do every day. The routinary activities also prevent them from enjoying leisurely activities and rest. These two mothers are also concerned about their health as they have experienced elevated blood pressures, a typical health concern of those who are in their middle adult life. They attribute this to the work that they have to perform as mothers.

Sibling rivalry is also present among families with children with disabilities as parents tend to spend more time and resources to the child with special needs (Kumar, Thomas, & Deb, 2015). In this research, all of the mothers admit that they spend most, if not all of their time on their child with cerebral palsy as their immobility restricts them from doing activities of daily living. This causes their children without disability to be jealous and have untoward behavior. The emotional quality of the relationship among peers can cause harmony or disunity among siblings (Santrock, 2011).

Since the mothers in the study are full time housewives, there is a need for them to budget their husband's earnings properly. Josie relies on the help of relatives as no one else has volunteered to take care of her daughter. Allocation of resources for food, utilities, education, transportation and therapy can be difficult as their husband's salary is the sole income support for their family. All the participants agreed that this creates stress among them.

Nora and Dina mentioned that disciplining their children is one of their parental roles. They view discipline as important because they wanted their children to grow up to be responsible. Despite the fact that their children have a disability, they want their children to be well-behaved. However, there are parents who would be more indulgent towards their child with disability because they want their children to be happy and this is perceived to ease away the difficulties of the condition (Knoblauch & McLane, 1999).

Stressors and Concerns of Mothers with Children with Cerebral Palsy

When asked about their stressors and concerns, the mothers had different responses and different reactions. They described their concerns as taxing physically, financially and, maritally. The enormous tasks and responsibilities that they have in rearing a child with cerebral palsy makes them feel stressed and deeply concerned. Given this, the researcher named the first theme extracted as taxing. Table 2 presents the answers.

Table 2. Taxing

| Theme | Code | Data Extract |
|--------|-------------------------------|--|
| Taxing | Strenuous physical activities | <p><i>Kailangan ko siyang paliguan, pakainin at pasanin para makapunta sa therapy</i></p> <p>I need to bathe, feed and carry them so that they can go to therapy (Bea)</p> <p><i>Nagtatrabaho ako nang mabigat at wala na akong oras sa sarili ko. Napakahirap alagaan ng anak ko.</i></p> <p>I work hard and I don't have time for myself. It is difficult to take care of my child. (Dina)</p> |
| | Financial issues | <p><i>Mahal ang gamot at therapy, di ko kayang magka-yaya, Nakaka stress.</i></p> <p>Medicine and therapy are expensive. I can't afford to have a nanny. It is so stressful. (Nylyn)</p> |
| | Marital Disputes | <p><i>Sabi ng asawa ko nung hiniwalayan ako, Basura ka dahil nanganak ka ng ganyan</i></p> <p>My husband told me when we got separated that I am garbage because I bore a child like that (Josie)</p> |

As mentioned earlier, routinary strenuous physical activities create stress among the mothers. Carrying an 11-year old child from their place of residence to the therapy center is indeed taxing for Bea who does not have money for transportation. Further, if ever she has extra money earned from the overtime pay of her husband, there are times wherein taxi and tricycle drivers refuse to give them a ride as it is difficult to board and alight a passenger with cerebral palsy. Despite the difficulty, she does this out of love for her child.

On the other hand, Dina complains that her household work is difficult and that she lacks time for herself. Oftentimes, parents who have children with disabilities have lesser time for themselves and this creates marital tension and other problems (Ahmad, & Khanam, 2016). Lack of relaxation, exercise and personal time contributes to stress and can also contribute to chronic health conditions (Stults-Kolehmainen & Sinha, 2014).

Perhaps the most taxing factor that contributes to stress would be to note that a significant life partner would call it quits. Having a child with disability creates marital discord and divorce (Sobsey, 2004) Josie said that she has suffered from verbal abuse from her husband since he learned that their baby has cerebral palsy. She was blamed all the time and was publicly humiliated for bearing a child with a disability. When they separated, her husband told her, “*Basura ka dahil nanganak ka ng ganyan!*” (You are garbage because you bore that child.). This caused her many sleepless nights and self-blame. However, Josie had to think of her child. She sought support from her relatives and is now trying her best to support her child. She mentioned that she has to be strong for her child to have a good future.

The second theme extracted from their narratives is on their child’s future. Parents who have children with disabilities are apprehensive about their children’s future as they recognize the fact that no one might take care of them when they are already old or have passed (Todd & Jones, 2005). Parents naturally would want their children to be successful and independent. While it is true that there are persons with disabilities who live independently, persons with severe levels of cerebral palsy cannot do so. Table 3 presents their response.

Table 3. Future

| Theme | Code | Data Extract |
|--------|---|--|
| Future | Future caregivers of child | Paano na sila kung wala kami? Sino ang mag-aalaga? (Nylyn, Bea, Mhel, MJ) |
| | Welfare and well being of their child with cerebral palsy | Sana maunang mamatay ang anak ko kaysa sa akin. Kawawa siya kapag nauna akong mamatay. I hope that my child dies before me. What a pity it is for him if I die first. (Dang) |
| | | Mapapanatag lang ako kung patay na siya bago ako I will only be at peace when my child dies before me (Josie) |
| | | Kawawa talaga ang anak ko kapag wala na ako What a pity it is for my child when I am gone (Dang, Nora) |

Future caregivers of their children are a concern of the parents. Since the participants are already in their middle adulthood stage, they think about the inevitability of death as some of them they have experienced chronic illnesses such as hypertension and diabetes. Middle adults somewhat think of the possibility of death as they see their colleagues die (de Klerk, 2013). Further, as PCPI is located near the South Cemetery, it is inevitable to think about death as they see funeral processions almost every day.

There are participants who wish that their children die before them. They say that it is very stressful for them to think that they will leave their children who definitely cannot fend for themselves when they become adults. Persons with severe levels of cerebral palsy need lifelong care and support (Hallahan, Kauffman & Pullen, 2012). In the context of Filipino tradition that though it goes against the grain to have children die before their parents, the participants feel that they do not want their children to be at the mercy of their relatives or worse, charitable institutions.

Coping of Mothers with Children with Cerebral Palsy

People who have undergone stressful situations learn cognitive strategies to cope (Santrock, 2011).

Table 4. Beliefs

| Theme | Code | Data Extract |
|---------|-----------------------------|--|
| Beliefs | Resilience | Matatag ako. Di ako natitinag I am resilient. I cannot be moved. (Bea, MJ) |
| | Religious beliefs | Hindi yan ibibigay sa akin ng Diyos nang di ko kaya God won't give it to me if I cannot triumph over it. (Nylyn) |
| | Going with the flow of life | Sumusunod lang ako sa agos ng buhay, bahala na. I just go with the flow of life, what will be will be. (Dang) |

Culturally, Filipinos have a concept of “kaya.” We have an “I can do it” attitude whenever faced with stressors. *Katatagan*, with the closest semantic equivalent of *resilience* often describes the Filipino if faced with adverse conditions. Both MJ and Bea say that they cannot be moved by the situation of their child.

Religion is associated with well-being (Santrock, 2011). Because of the strong Filipino Christian tradition of faith in God, difficult situations appear to have hope. Oftentimes, we believe that God will not give us troubles more than we can bear. Embedded in this statement is the belief that God will help us triumph over difficult situations in life.

Our concept of “bahala na” enables Dang to just go with the flow. She lives one day at a time and said that she has lesser stress because of it. She admits that she could not solve all of her problems in one sitting.

CONCLUSIONS

Parenting practices are operationalized as household management and this involves completion of household chores. Because of the financial limitations and the load of daily household work of the participants, the responses seemed to be limited.

The stressors are physically, financially and maritally taxing to the participants as they are faced with an enormous task of raising a child with a severe disability. The future of their child with cerebral palsy is also a cause of stress.

Positive beliefs and their faith in God has helped the parents cope with the condition of their children.

RECOMMENDATIONS

Given the results of the study, the following are recommended:

The research could be conducted as a quantitative research to different socio-economic groups in order to identify if there are significant differences in parenting, stress, and coping across income groups. Responses from different age levels of children and mothers can also be considered to check if there is a trend in response. Differences of responses between fathers and mothers could also be investigated on. Replication of this research on mothers who have children with autism, intellectual disability and sensorial disabilities can also be done to compare responses.

Identification of more themes for stressors could be done with a bigger sample size. Future researches could be collaborated with the Cerebral Palsy Association of the Philippines as this organization has a nation-wide scope.

Creation of a psychosocial program that addresses the needs of the mothers must be formulated. Different ways to alleviate stress and identification of a network of financial, human and psychosocial support must be done in order to minimize the problems that disability brings.

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