

Quality of Life of Parents of Filipino Children with Special Needs

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ABSTRACT

Children with special needs (CWSN) experience disability in various areas. The birth of a child with special needs causes stress in the family, most especially among parents, consequently affecting parental quality of life (QOL).

This paper describes the QOL of parents of Filipino CWSN and examined the determinants of parental QOL using a mixed method design. The participants are parents of Filipino CWSN (n=76) and were asked to answer the World Health Organization Quality of Life-Brief (WHOQOL-BREF) Questionnaire Filipino Version. Interviews were also conducted among a sub-sample of the parents who answered the questionnaire earlier (n=6).

Results indicate that parental educational attainment, annual income, child's comorbid conditions and length of time in therapy are the best indicators of parental QOL, as parents of Filipino children with special needs express and exhibit negative stresses that affect their lives.

The researcher recommends family intervention programs that take into account the aforementioned variables and parental advocacy.

Keywords: *Quality of Life, parents, children with special needs*

Disability interferes with an individual's ability to engage in activities expected for his functioning throughout the lifespan. Various authors have described how such disability can affect a child's quality of life, requiring special attention to their unique needs. It is imperative to note that although disability affects the individual, attention should also be given to its effects on the people around them particularly their parents. The problems they face and the issues they address are different from parents with regular children.

Previous studies attempted to describe the stresses, issues, and problems that a child's disability places on their families. The literature describes parental psychological issues, physical stresses, socioeconomic roadblocks, to name a few, as co-morbid conditions to raising a child with special needs. Although this is beneficial in planning individual programs that address parental issue-specific problems, a more dynamic and holistic framework should be considered to show how these issues are related with one another.

Children's Disability and its Effects on the Family

'Disability' has been defined as a physical or mental impairment that substantially limits one or more psychological or anatomical functions of an individual or activities of such individual (Senate and the House of Representatives of the Philippines (1992). Republic Act 7277 Magna Carta for Disabled Person Philippines: Congress of the Philippines). Because of such restriction, the individual is not able to perform life roles normally expected for his age, consequently affecting his life.

Children affected by disabilities experience difficulty in their ability to live a normal life, most of the time requiring special care and assistance (Azaula, Msall, Buck et al, 2000; Leonard, Johnson & Brust, 1993). This places a great deal of stress on the family, most especially, their parents. Lazaru & Folkman (1984), Hill & McCubbin (1958, 1984) proposed two models of family stress, both of which cite the birth of the child who has special needs as the stressful factor.

Stress has been a common topic among scholars who look into the effects of a child's disability on the family, especially the parents. The stress starts when a child has been diagnosed as having a disability. It is as if the parents attain a "symbolic death" of their dream to see their child live a normal life (Lerner, 1995). These stresses continue on to include prolonged dependency and demands for special care (Howard, 1978), disappointments with delayed developmental milestones (Bentovim, 1972) and worry regarding future self-sufficiency (Wing, 1985; Wolf & Goldberg, 1986). Stress has been linked to psychological distress, emotional anxiety, physical strain, and economic burden to name a few.

Parenting children with special needs may have an adverse effect on their general well-being (Cummings, Bayley & Rie, 1966; DeMyer, 1979). Boyd (2002) states that if support is not sought, development of depression and anxiety was postulated for mothers. Mothers of children with autism (CWA) and children with behavior disorders are at a risk of experiencing dysphoria, which seems to be linked to the stresses brought on by parenting a child with special needs (Dumas, 1991).

Stress and health are related (Serafino, 2005). The daunting task of caring for a CWSN requires special parenting skills which can be detrimental to the physical health of their parents. Raina, O'Donnell, Rosenbaum, Brenhaut, Walter, Russel, Swinton, Zhu & Wood (2005) found that the most important predictors of these children's caregivers were the behavior of their child, the demands of the task, and the family function. Murphy, Christian, Caplin & Young's (2007) study findings show that caregiver health worsens due to the consequent lack of time, a lack of control, and decreased psychosocial energy brought about by their roles.

Being a parent of a child who has special needs has been described as complicated, challenging, and frustrating (Gargiulo, 1985). Financial concerns further exacerbate their situation. With the perceived lack of financial support from the Philippine government (Joaquin, 2002), parents are more inclined to be financially supportive to their children's needs (Binoya, 2003).

Seltzer and Greenberg (2003) noted that parents of children with developmental disabilities from larger families had lower rates of employment. In a similar study conducted in the Philippines, half of the maternal subjects reported to have given up their careers and devoted their time and energy to the caring of their child (Liwag, 1987). Single parents of CWSN also find themselves at an additional disadvantage as discussed in Foronda's study (1998).

The 24/7 demands can impact how parents relate to their spouses and to other members of the family (Licuan, 2007). The lack of public knowledge and understating regarding the true nature of autism creates stigma (Foronda, 1998).

There is a tendency for parents to perceive themselves as stigmatized by their child's condition, with stronger affinities to mothers than fathers (Gray, 2008).

Communication and relationship problems are usually seen between the parents of a child with special needs. This can cause marital distress, if not an eventual separation between them (Sabbeth & Laventhal, 1984). The incidence of marital conflict is not uncommon (Farber, 1959) in families that have a child with mental retardation. In contrast, there are actually some families of CWSN who experience no more than the same problems in marital relationships in comparison with regular families (Bernard, 1974; Dorner 1975; Martin 1975; Patterson, 1991; Weisbren, 1980), with marriages being reported to have improved after the birth and diagnosis of the child as having a disability (Schwab, 1989; Klein & Schive, 2001).

Wolf, Noh & Fishman (1989) gave a brief report on the psychological effects of parental stress on the parents of autistic children and included isolation from family and friends as an important life stressor on these types of parents. Dunn, Burbine, Bowers & Dunn (2001) strengthened this claim by looking at how lack of social support contributed to negative outcomes of depression, social isolation, and spousal relationship problems.

Quality of Life (QOL) of Parents of CWSN

Quality of Life has been described in literature as a person's dynamic appraisal of his life in relation to various domains as it relates to his environment (World Health Organization, 1997). A person's QOL is not a single phenomenon

but rather an interplay between and among several dimensions. Health-care professionals generally agree on four QOL dimensions: physical, psychological, social, and spiritual (Hilderley, 2001).

The impetus on research concerning the quality of life of individuals with disabilities has been seen for the past twenty years (Hughes & Hwang, 1996; Schalock, 1997, 2000), but not until recently has there been more focus on its effect on parental QOL.

Yilmaz, Cetinkaya & Caglar (2005) found that the mothers of children with cerebral palsy are more at risk for depression compared to mothers with regular children. Eker and Tuzun (2004) conducted a similar study and results show significantly lower scores, except the physical subscale, of these mothers compared to the control comparison group. They also noted significant correlations between the child's motor disability and the QOL scores of their mothers. O' Lafur, Gudmundsson and Masson (2002) noted that mothers of children with mental disorders reported a poor quality of life, with high prevalence for mental disorders themselves. Using the WHOQOL-BREF, Leung & Li-Tsang (2003) and Rotor (2006) conducted similar studies on the QOL of parents who have children with disabilities. Both studies confirmed that caring, raising, and parenting a CWSN compromised parental QOL, similar to the idea proposed by Evans, Dingus & Haselkorn (1993).

Research in the past has pointed out that the more intensive the level of assistance given to the disabled child, the lower the QOL of the caregiver (Unalan, Gencosmaoglu, Akgun, Karamehmetoglu, Tuna & Ones, 2001 cited in Leung and Li-Tsang, 2003 and Rotor, 2006).

Moreover, the quality of life of these special families is changed as the family and its members experience the dynamics of life. The domains of the family are interrelated and affect each other as well (Park, Turnbull & Turnbull, 2002).

This study describes the quality of life of parents of Filipino children with special needs and the problems they face. The field of special education in the Philippines could use this in understanding the needs of these parents.

The study involved the use of a Filipino translated tool, the WHOQOL-BREF to determine quality of life. Subjects were parents of Filipino children with special needs, residing or whose child is receiving intervention within Metro Manila only. Exceptionalities and degrees of severity were not considered as variables, so a general sample population was considered for the study. Data on parental quality of life are presented based on the responses of the parents of Filipino children with special needs only and were not compared to those with regular children. The chi square analysis was limited to the variables included in the demographics and subjects' responses to fully utilize the data.

Methodology

This study employed a mixed method design which includes an integration of both quantitative and qualitative approaches, as recently seen in modern research. The first part of the study employed a descriptive-correlational method based on the data gathered using the parents' information sheet and WHOQOL-BREF questionnaire.

It describes the different variables related to the demographics of the population sampled and their QOL scores on the different domains. Consequently, such data were analyzed using chi square to determine their relationship with parental QOL. The second part of the study employed a descriptive qualitative approach (Sandelowski, 2000; Neergard 2009) of the experiences of parents of CWSN in the light of their quality of life, as derived from the one-on-one interviews conducted by the researcher with the respondents. Thematic analysis of the qualitative data followed.

The study comprised three phases. Phase one involved purposive sampling method. One hundred parents of Filipino CWSN were given the WHOQOL-BREF questionnaire in the different settings aforementioned. A minimum response rate of 70% was set.

Phase two involved data gathering. On the first stage, 100 possible participants were given a packet each. From the 100 questionnaires, 78 were returned, of which 76 had viable data and met the inclusion criteria set by the researcher. On the second stage, the data were encoded in MS Excel 2003. The scores on the 26-item WHOQOL-BREF questionnaire were summed up in each domain using the prescribed scoring guideline given by the World Health Organization. The average of the answered items represented the response to the unanswered item. Descriptive statistics and chi square were done to describe the characteristics of the subjects and their answers on WHOQOL-BREF Filipino version questionnaire and to present how the characteristics of the subjects correlate with their quality of life as measured by the said questionnaire using SPSS 16.

The researcher set an inclusion criterion which the respondent parents must meet for their data to qualify for analysis. They are either a father and/or a mother of a child who has been classified as having special needs, residing and/or whose child is attending intervention programs in Metro Manila. These respondents consented to participate and answered at least 80% the WHOQOL-BREF questionnaire.

Phase three of the research is the qualitative data gathering where six key informants, who were part of the group of participants during the second phase of the study, participated in one-on-one interviews. From the interviews, themes were formed and analyzed.

This study used the WHOQOL-BREF Filipino version as its main tool to measure the quality of life of parents of Filipino children with special needs. This questionnaire is the short version of the WHOQOL-100 and allows detailed assessment of different facets under the domains of Physical health, Psychological, Social relationships, and Environment. Numerous studies have examined the use of the tool and found it valid, specific and sensitive. The English version is available for download at www.who.org, while the Filipino version is available upon request from the said website.

During the one-on-one interview, the researcher adapted "Conducting Focus Group Interviews" guide by the USAID Center for Development Information and Evaluation (1996). The transcribed data underwent thematic analysis and was coded using MS Excel Spreadsheets. For the purpose of this research, the 10-step coding process recommended by Hancock (2002) was utilized.

Presentation and Analysis of Data

Profile of the Participants

Seventy-eight questionnaires were returned to the researcher. From the 78, 76 were able to meet the inclusion criteria and contained viable data.

Seventy-six percent (76%) of the respondents were female. Age distribution were classified into five subgroups with ages 31-40 making up the majority at 36% and ages 51-60 at comprising 9% only. As for educational attainment, 73% attained college degrees while 9% reached only secondary education levels. Majority of the respondents, 91%, are married. Based on the respondents' answers, 32% had an annual gross income of more than P501,100; 13% earned P11, 000-50,000; and 12% earned P301,000-500,000. Of the total respondents, 38% had two offspring; and 18% have only one child. Autism accounts for the most frequent case at 33% (25), while hearing impairment had the lowest frequency.

Sixty-nine percent of the respondents had a male child with disabilities. The children's age range from one to twenty years old and above. Thirty-three percent (33%) of the parents have children ages 1-5 years. As for severity of condition, 61% of the respondents reported that the condition of their child is mild; 22% of the cases are moderate, and 4% are severe. Comorbid conditions of the CWSN were also asked and 71% answered none. Common conditions included obesity, mental retardation, and speech/language problems.

Sixty-four percent (64%) of the parents said that their CWSN are currently attending school; 50% of these children attend school daily. Aside from school,

97% said that their child receives therapeutic interventions, 49% of these children have three therapeutic programs (physical therapy, occupational therapy, speech and language therapy) in various therapy centers within Metro Manila.

Six of the 76 respondents were invited to participate in a one-on-one interview. Four of the six were females, 2 were males. All were married with an age range of 29-56 years old. Three were college teachers, one was a businessman, one was a dentist and one was a lawyer. Their CWSN's ages ranged from 6-16; 3 were males and 2 females. All the children are attending school, 5 of them were receiving therapeutic interventions. Two of the CWSN have been diagnosed with Autism; one had CP and comorbid Autism and Mental Retardation; one had Down Syndrome; and one had a physical im health impairment (G6PD Deficiency), a metabolic condition.

Quality of Life Profile

The QOL profiles of parents of Filipino CWSN were assessed using the WHOQOL-BREF Filipino Version across four domains, namely, Physical Health (D1), Psychological (D2), Social Relationships (D3) and Environment (D4). It has a total of 26 questions. Table 1 on the next page shows the mean scores for each domain.

Table 1 shows the mean QOL scores of the participants across all domains. The 2nd column is the mean of the raw scores, while the 3rd column is the mean of the transformed scores; which are standard scores for the tool. The questionnaire uses a five-point scale (5=highest; 1=lowest). The over-all QOL item shows a mean of 3.36, while item on general health is at 3.24; both are slightly

Table 1. Mean QOL Scores

Domain	Mean of Raw Scores	Mean Transformed Scores
D1- Physical Health	3.68	14.71
D2- Psychological	3.71	14.84
D3- Social Relationships	3.82	15.26
D4- Environment	3.44	13.75
Q1- Over-all QOL	3.36	13.42
Q2- General Health	3.24	12.96

Table 2. Distribution of the Four WHOQOL BREF Domain Scores

Domain	Mean			
	Filipino (Gomez, 2010) n=76	Filipino- Caregivers of CP Children (Rotor) n=22	HK Chinese Parents of children with disabilities* n=71	HK Chinese Parents of children with disabilities* n=76
Physical Health	14.71	13.96	13.96	14.60
Psychological	14.84	14.3	13.37	14.04
Social	15.26	14.3	13.41	14.17
Environment	13.75	12.9	12.05	12.98
Perceived QOL	3.36	3.28	n/a	n/a
Perceived Health State	3.24	3.28	n/a	n/a

above the midrange. Among the four QOL domains, Domain 3 (social relationships) has the highest mean at 3.82, which could mean that the parents are moderately satisfied with their ability to socially interact with the people in their lives. Domain 4 (environment) has a mean of 3.44, seen at the lowest rank; although still considered moderately satisfied, these parents do feel that among the other QOL domains, support from the environment and financial constraints is at the bottom.

Table 2 presents a comparison between the distributions of scores in the Four WHOQOL-BREF QOL Domain Scores of the author, plotted against data from previous studies of Rotor (2006) and Leung & Tsang (2003).

Based on the analysis, it is evident that data obtained by the author were higher compared to published data by the other two authors. Across all areas, the parents of Filipino CWSN who participated in this study showed higher scores on all four domains compared to caregivers of children with cerebral palsy (Rotor, 2006); and HK Chinese parents of children with and without disabilities (Leung & Tsang, 2003). Interestingly, across all domains, the respondents of this study fared higher than the scores presented by other research. The variables examined and contextual factors might attribute to this. Quality of life places importance on integrating the values and culture of the individual prior to generalization (WHO, 1997). This is the

rationale that guides the interpretation of this phenomenon.

Chi-Square Data Analysis. The chi-square test was used to determine whether there is a relationship between the different variables studied and the QOL scores. These are actual results of the correlational computations using SPSS 16.

Table 3 shows the specific facets related to each of the four domains of QOL.

WHOQOL-BREF Questionnaire identifies four Domains: Domain 1 (Physical Health) pertains to activities related to taking care of one's body; Domain 2 (Psychological) refers to the individual's psychological processes and his view of himself; Domain 3 (Social Relationships) pertains to how the individual relates with other people in his life; and Domain 4 (Environment) are various facets in relation to the physical environment where the individual lives in.

Table 3. WHOQOL- BREF Domains

Domain	Facets incorporated within domains
1. Physical Health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration
3. Social Relationships	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

Of the variables examined, a significant relationship to QOL domains was established with: parental education ($p= 0.01$) and income ($p= 0.045$) with Domain 4 (Environmental); CWSN's comorbid disability ($p= 0.04$) and number of days in school ($p= 0.02$) with Domain 1 (Physical Health); and CWSN's therapy ($p= 0.03$) on Domain 3 (Social Relationships).

The parental level of education ($p= 0.01$) is seen to have a relationship with the environmental domain of the parental QOL scores. Relationships on other domains were not significant enough. Such findings are similar to those of Soori (2004) and O'Brien & Jones (1999). Higher education leads to higher-paying jobs that can support the financial and healthcare needs, and address safety issues within the home and in the family's immediate community.

A relationship was seen between parental income ($p= 0.045$) on the environmental domain, among the other three. Authors do suggest looking at parental income, and to relate this to their

perceived QOL scores (Walker, Winkelstein, Land, Boyer, Quartey, Pham & Butz, 2007; Pahel, Rozier & Slade, 2007; Sach & Barton, 2009). They also point to the amount of parental income as a good predictor of QOL.

As to the relationship of comorbid conditions to the QOL scores of the parents, there is a significant relationship between such on the parents' physical health domain ($p=0.04$). The disability of the child greatly impacts the quality of life of parents (Leung and Li-Tsang, 2003; Rotor, 2006; Canam and Acorn, 1999; Williams et al. 2003; Raina, O'Donnel, Rosenbaum, Brenhaut, Walter, Russel, Swinton, Zhu, B. & Wood, 2005). Active medical comorbidities may account for the further reduction of parental quality of life, more particularly in the psychological domain as cited by Sant' Anna, Frey & Adreazza (2007). Comorbid conditions have been seen to have increased the level of severity of the child's conditions contributing to illness markers that might need more physical contact care.

Table 4. Summary of Chi-Square p Values

Variable	D1	D2	D3	D4
Age	0.17	0.81	0.39	0.75
Gender	0.65	0.67	0.70	0.43
Education	0.068	0.13	0.19	0.01
Income	0.50	0.52	0.23	0.045
No. of Children	0.099	0.41	0.61	0.95
Child's Age	0.19	0.31	0.98	0.45
Child's Gender	0.10	0.26	0.57	0.32
Comorbid	0.04	0.19	0.19	0.08
Severity	0.19	0.77	0.58	0.12
Attends School	0.67	0.32	0.53	0.076
Days in School	0.02	0.47	0.61	0.69
Receives Therapy	0.84	0.53	0.03	0.38
Days in Therapy	0.88	0.55	0.35	0.82
Years in Therapy	0.52	0.48	0.72	0.80
Storm Factor	0.24	0.53	0.37	0.71
Caregiver	0.45	0.15	0.27	0.06

The chi-square analysis (see Table 4) points out that there is no statistical relationship between the QOL domains and parental age and gender and the CWSN's age, gender, severity, school attendance and number days in therapy. Parental age and gender, and the age and gender of the child do not predict parental QOL outcome. Although one might think that the severity of the child's condition can affect parental QOL, data from this research does not support this. Moreover, increased frequency of attendance in school and in therapeutic programs does not improve general parental QOL.

Upon comparison between parental gender and QOL, results show no relationship. Similar findings on available literature depict the same situation. Authors of various studies relate how mothers are far more vulnerable to be affected compared to their spouses. Fathers were seen to adapt relatively well, probably even better than the mothers (Rodrigue, Morgan and Geffken, 1992). Del Rosario (2008) noted that in the initial stages of the child's diagnosis, emotions of disbelief, denial, sadness and devastation are seen among fathers, but these usually lessen over time. Perhaps the stress-coping model or a cognitive adaptation model could be attributed for this phenomenon. In a local study conducted by Rotor (2006), she noted that in three out of the four domains (except for social relationships) females scored lower. No correlation was performed, but the author explained that the majority of the respondents were females, a feature likewise shared by this study. On the one hand, they are the constant primary caregivers of the CWSN. The constant contact care they provide to the CWSN might be the reason as to why they score lower on some domains. On the other hand, since they accompany the

child in therapy and in school, between the two parents, they have more social activity, and get to have more social support compared to the fathers.

Child gender does not have a significant relationship to the scores of the parents on all four domains. This finding is similar to the results presented by several authors (White-Koning, Arnaud, Diskinson, Thyen, Beckung, Fauconnier, McManus, et al 2007; Goldbeck, 2006; Vaikaitiene 2006; Halterman, Yoos, Anson, Arcoleo & McMullen, 2005) who conclude that the gender of the child does not affect the QOL of the parents.

The severity of the child's condition was found to be not related to parental QOL score, but the highest relationship was seen on the physical health and environmental domains of their QOL scores. These results were contrary to the findings of several more recent studies (Mobarak, 2000; Wang, Turnbull, Summers, Little, Poston, Mannan & Turnbull, 2004; Arnaud, 2007) which point out that the degree of severity of the child's condition significantly lowers the perceived quality of life of these parents. Peeters, Boersma, and Koopman (2008) discussed the development a stress-coping model which mediates the predictors of health-related quality of life, including severity, explaining that no significant relationship occurred among the subjects.

There was no relationship found on parental QOL scores when the CWSN attend school. However, interestingly, chi-square relationship was established between the number of days in school ($p=0.02$) and when CWSN attend therapy ($p=0.03$) on the physical health domain of the parents. When children are in school, parents have more time to perform daily

activities and take rests (Foronda, 1998; Liwag, 1997). Since most parents go along with their CWSN as they attend school or therapy programs, they have a chance to interact and socialize with other parents (Rotor, 2006).

Thematic Analysis. The problems of parents of Filipino children with special needs were cast using thematic analysis of the one-on-one interviews with the six KIPs. They are presented and expounded on in the subsequent paragraphs.

Four Ps of Parental Life. From the transcribed interviews, the researcher identified four aspects of parental life which are affected by the demands of parenting CWSN. Upon discreet introspection, the researcher was able to identify areas within the “sphere” of these parents that have been affected by CWSN. These main areas were greatly influenced by the work of the WHO-QOL Team, the same team responsible for the development of the questionnaire used by the researcher.

Table 5 summarizes and presents the 4 Ps of parental life affected by having a CWSN and their corresponding definitions. This is the product of the researcher’s effort to apply thematic analysis on existing quality of life researches (WHO, 1996; Fhay & O’ Cinneide, 2007; Allison, Locker & Feine, 1997). It describes four aspects of parental life and the facets that that the researcher used to define each.

Physique refers to the physical health status of the parents. The fact that the most number of responses related to this dimension reflects an increase in energy exerted to caring and managing CWSN. Low levels of rest were also evident. Instead of pursuing rest, parents opt to consider the pressing needs and concerns of their CWSN, this can greatly influence their ability to perform the demands and requirements of their work or even the cessation of it. Participant 4 even expressed giving up a career. “You have to spend more of your time with her because she has special needs. Six years I refrained from work!”

Table 5. Four Ps of Parental Life

Four P’s of Parental Life	
<i>Physique</i>	is defined as the physical health dimension. This includes the amount of energy exerted, rest acquired, and the capacity to work.
<i>Psyche</i>	are clusters of psychological dimensions encompassing negative and positive feelings, self-esteem, spirituality, personal beliefs, ability to concentrate or focus and worries.
<i>Polarity</i>	pertains to social relationships maintained within the context of the parent. This includes spousal relations, offspring relations, relationship with extended family members and social supports from people outside the family.
<i>Perimeter</i>	is the dimension of the parental life that describes various contextual factors; includes financial resources, physical safety and security, health care, home and community environment, opportunities for acquiring new information and skills, leisure participation and transport systems.

Local researchers, such as Foronda (1998) and Liwag (1997) pointed out how the stressful life of a parent of CWSN can impact their physical health. Such stress can result from the child's behavioral problems (Foronda 1998; Bayle, 2007), or delicate nature that he cannot be left alone (Binoya, 2003), physical and home environment imbalance (Mejia, 2009), or adopting an overly-involved parental role (Badalgo, 2009; Alonzo, 2005). Liwag (1997) and Del Rosario (2008) also noted how some parents needed to resign from work to attend to the needs of their child.

Psyche. These are clusters of psychological processes that range from emotions to cognitive processes. Caring for a child whose needs are more than the mundane puts additional strain on the psychological well-being of the parents. The child's behavior was identified as a problem. Participant 1 said that "there are times you feel ashamed because she is rowdy." Participant 4 said, "You feel that this would not happen to you. When it did, it felt like my world came crumbling down."

These parents of CWSN face crisis that challenge their day to day lives (Camara, 2007). Their negative feelings are results of: the stress that they endure across their lifespan (Alvares, 2004; del Rosario 2008; Bayle, 2007; Alonzo, 2005; Mejia, 2009; Jamora, 2009); worries of an uncertain future (del Rosario, 2008); a feeling of disadvantage (Binoya, 2003; Licuan, 2007; Jamora, 2009) and educational intervention (Joaquin, 2002; Sandoval, 2001; del Rosario, 2008;).

Conversely, parents also express their positive feelings towards the child and the condition they are in currently. Participant 2 said that "...it brought the family together." Participant 4 explains further: "The positive aspect for us,

perhaps in a way, when she came to us, it seemed a humbling experience for us... Now, if I look at it, it seems it was a lot better that she came along."

Mejia (2009) concludes that positive beliefs and positive traits are coping mechanisms that parents develop so they can mediate the child's development and improvement. A positive and hopeful outlook among fathers of children with autism (Del Rosario, 2008) was also discussed as an effect of the child's diagnosis on their parents. Go (2008) implies that these motivating factor tends to overlook the negatives. Focusing more on the positive could be overridden by love.

Moreover, the addition of CWSN in the family creates an atmosphere that lowers the self-esteem of the parents. They feel that they have lost a sense of their selves and doubts fill their minds. Constant worries are reflected throughout the interviews. Effects on their family dynamics, especially the reactions and feelings of the regular offspring also account for this. The majority of their worries dwelt on the uncertainty of the future. Participant 1 said "For one, I didn't want to have another child anymore... With her brother, it seems why is it always her? That is what I hear from her brother. It is difficult to balance your time... there are times when he gets jealous of her," while Participant 4 stated "I felt left out." Additionally, participant said "... planning for the future of course is a concern. He is not an ordinary kid that even when he has no more parents that will support, he can survive."

Parental coping capacities of Filipino parents of CWSN are mediated by various factors. One of them is the fear of having another child (Binoya et al,

2003). Due to the daunting tasks of parenting, the parents are not able to realize their personal needs of expanding their family. And since their working capacity has been compromised (Liwag, 1997) feelings of personal and professional growth is affected and lowered among these parents. The worries and anxieties of these parents are similar to those described by various researchers (Sorongon, 2008; del Rosario, 2008; Laigo, 2007; Alonzo, 2005; Mejia, 2009; Jamora, 2009, Joaquin, 2002, Sandoval, 2001). Such should be properly understood, processed, and integrated into a family-centered intervention program (Gaw, 2000; Licuan, 2007; Rey-Matias, 2009).

Polarity. Social relationships between spouses were described as adequate. Most of the effect was seen on the siblings' actions and reactions, as described previously. Participant 2 said, "Well it seems that throughout the years, there are signs that he (brother) has accepted that fact..." and similarly Participant 4 articulated "... her brother, as early as now, he knows his responsibility (towards the CWSN). When he gets married, he has accepted that."

Problems and concerns of the siblings of children with special needs have more recently been explored. The siblings' acceptance of the CWSNs' condition and consequent future roles that they will assume mediate this stress (Sorongon, 2008; Laizo, 2007). Siblings are also seen to have benefited from the condition of their CWSN siblings and have been described to have acquired positive effects on their levels of maturity, sense of life, social skills, and responsibility (Laizo, 2007)

The parents also talked about social supports given to them by the extended family members. Being able to talk with other people helps parents cope

with their current life situations (Del Rosario, 2008; Bayle, 2007; Mejia, 2009; Jamora, 2009). Additional support is sought from the people around them, most especially the yayas, in managing the CWSN. The motivating factors that these yayas display, mostly out of love (Go, 2008), provide comfort and alleviate some of the problems that parents go through. On the other hand, views of other people outside their immediate family seem to be a concern to the parents. Participant 1 said, "It's just that there are times when we are in public places... she acts out differently. There are times that you feel ashamed because of her. It's just that. But I do not denounce the child."

The need for public awareness and education in correct information about the various disabling conditions of children is one of the concerns that parents of CWSN call for. Through interdisciplinary (Licuan, 2007), transdisciplinary (Rey-Matias, 2009) and family-centered interventions (Gaw, 2000) parental stress can be alleviated.

Perimeter. This is the environmental and contextual dimension to which the parents have been affected. The surrounding perimeter encompasses everything and anything external to the individual. It represents an extension of one's surroundings, something that transcends the space and time inherent to situations and contexts. The pressing specific facet specific would be on their financial resources, where all the respondents commented on the high cost of raising CWSN. Particularly, Participant 2 said, "...and of course you have to provide for his needs, we cannot afford that only one of us works, because it is expensive... their needs are far more expensive." This is parallel to what participant 4 exposed, "Yes, you really have to have a budget for that. Her

schooling is relatively more expensive than the normal. Then she has therapies. So in a way, our finances are affected."

Concerns of finances and parental ability to support children stem from the fact that special education, therapies, and other interventions are expensive and long-term, if not difficult to seek (Del Rosario, 2008; Licuan, 2007; Mejia, 2009; Rey-Matias, 2009; Jamora, 2009; Sandoval, 2002; Joaquin, 2001; Gaw, 2000).

The degree of safety and security also emerged from the interview. Parents need assurance that they would have a home and community that would be supportive and not suppressive; one that promotes health rather than merely reactive to disease. Participant 5 worries, "Because you cannot monitor what the other kids are eating. What if he sees the food of his classmates that he wants to taste?" While Participant 6 elaborates, "He and his classmates often share their food with each other. So I am not completely solved that he is 100 % protected or he does not eat prohibited foods for him."

As the birth of CWSN into the family is unforeseen, so is their future. The unpredictable nature of a child's condition can have grave effects on the child's health and safety. Parents have to deal with this too (Del Rosario, 2008; Licuan, 2007; Sandoval, 2001). They need the assurance that their child can enjoy a supportive environment, and this serves as a stress mediator rather than a barrier to parental satisfaction (Mejia, 2009).

There is limited participation among these parents in leisurely recreation. Taking care of the child prevents them from having the time and the resource to indulge in activities they enjoyed before. In one excerpt, Participant

2 said "Of course there are times you have to forego personal wants, because there are other priorities." Similarly, Participant 4 expressed, "It has affected me in the sense that I cannot go out. He (CWSN) is always with me than the rest of the family, and he does not want me to go out."

Del Rosario (2008) explained that the decrease in the level of social interaction can be due to the increased time demands that parents need to meet. In an attempt to prevent the consequences of such, parents are encouraged to discreetly find time to engage in leisure and recreation such as going to social gatherings, playing sport, and dancing (Bayle, 2007).

Conclusions and Recommendations

In conclusion, this study has found out that parents of Filipino children with special needs experience negative stresses related to the physique, psyche, polarities, and perimeter aspects of their life. Furthermore, it was found out that parental educational attainment, annual income, and CWSN's comorbid conditions and length of time in intervention programs have the most level of significant relationship with parental quality of life.

If there are variables that can predict the outcomes of quality of life among parents of children with special needs, it is prudent to include them and focus on them more when creating programs. Because of the variability of these QOL predictors from one another, it is, therefore, likely that the concerned would adopt a holistic and integrative frame of mind in designing such programs. These predictors can also be

used in screening parents who might be at risk from developing problems because of their condition. The creation of an outcome-based assessment tool that incorporates these variables and includes other parental quality of life predictors is further suggested. The identified life aspects that are affected by parenting CWSN can be used and further triangulated with existing knowledge to create programs specifically directed towards parents in the early stages of identification of their child's condition. Such programs can inform parents on what to expect.

The findings of this study could be utilized in the creation of parental support programs at the school and community level that could address the specific needs of parents whose quality of life is affected by CWSN. Furthermore, the results of this study can aid special education researchers whose area of choice is parental involvement in the education process of CWSN. Findings of this study can help create effective and relevant programs that address these parents' needs.

With the data provided in this research, parents can further understand the issues they face in life and lead them to work on the advocacy of their rights. The results can influence them to seek help and avail themselves of services that would address their needs. The data gathered from this study could also inform policy makers who can draft laws that will mandate the inclusion of the family in the education of children with special needs.

Given the framework suggested by the author, a more extensive exploration of the constructs and hypothesis presented in the context of Filipino culture should be explored. The

fact that the respondents showed higher mean QOL scores compared to parents of children without disabilities (Leung and Li-Tsang, 2003) needs more judicious evidence.

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