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Predictors of the Quality of Life Among Parents/Caregivers with Children with Special Health Care Needs (CSHCN)

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Abstract. This study investigates the predictors of the quality of life of parents/caregivers who have children with special health care needs (CSHCNs). One hundred and seven parents/caregivers with CSHCN were asked to answer a paper and pen questionnaire on profile about themselves and their child with special health care needs. Also, they answered a WHO quality of life questionnaire and the multidimensional scale of perceived social support. When all the independent variables (perceived social support from significant other, family, friends, income, gender of the parent/caregiver, and presence of intervention) were entered into the regression equation, the model yielded a significant result, F=7.44 at p<.01 and it contributes 26.7% to the variance of quality of life. But, only two variables out of six-the perceived social support from the significant other and income-are the significant predictors to quality of life, with β=0.34, t=2.62, p<.01 and β=0.311, t=3.48, p<.01.

Keywords. Quality of Life, Perceived Social Support, Children with Special Health Care Needs, Parents, Caregivers

1.Introduction

A child is considered the best gift any parents could have. All parents want to have a perfect child. However, in reality that is not the case. Some children have special health care needs that challenge parents' patience, love, resiliency, understanding, and even finances, among others.

The Maternal and Child Health Bureau (2010) defines children with special health care needs or CSHCN as those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type and or amount beyond that required by developmentally normal children. CSHCN include children with conditions like asthma, diabetes, obesity, birth defects, developmental disabilities such as autism, cerebral palsy, mental retardation, and mental illness. CSHCN are born into all sorts of families. Regardless of the socio-economic status, one cannot anticipate the arrival of a newborn with special health care needs, nor one is ever prepared to be a parent of a CSHCN. Although such a birth is usually an unanticipated event, most families learn to accept, and sometimes rejoice in its occurrence (Seligman & Darling, 2007). Parents of children with special health care needs have reported positive contributions that their children have on their quality of life like fostering the development of patience, love, compassion, and tolerance, improved relations with family members (Kausar, Jevne, & Sobsey, 2003, as cited by Meral & Cavkaytar, 2012), and positive changes in spiritual values (Trute, Heibert-Murphy, & Levine, 2007). On the other hand, according to Gomez and Gomez (2013), parenting a CSHCN may have an adverse effect on their general well-being, specifically the parental or caregivers' quality of life. Parents/caregivers who have children with special health care needs are often reported to have physical and psychological distress related to caring for their children, thus, affecting their quality of life (Leung & Li-Tsang, 2013). Quality of Life (QOL) represents one of the comprehensive, multidimensional outcome measures that is based on the individual's subjective perception regarding several aspects of life experiences (WHO, 1997).

One of the factors that may affect the quality of life of a parent or caregiver is perceived social support. The use of social support is an external coping strategy that is believed and has been shown to reduce family stress (Beckman & Pokorni, 1988; Berry & Hardman, 1998). Other factors that may affect quality of life of parents or caregivers are the socio-demographic factors (Cho & Kang, 2014) like income and gender, and the interventions provided to the child and family. Financial challenges are considered one of the most common concerns for parents and caregivers with CSHCN and showed that monthly family income was positively associated with the caregivers' quality of life (Dardas & Ahmad, 2014). Other factors such as gender (Dabrowska & Pisula, 2010), and intervention given to the child with special health care needs influences family wellness and the caregiver's quality of life (Kidd & Kaczmarek, 2010). A lot of studies have been conducted on the quality of life of individuals with special health care needs, tool little on the parents/caregivers. Thus, this study aims to look at the predictors, specifically perceived social support, socio-demographic factors, and intervention, to the quality of life of parents/caregivers with CSHCN.

2. Methodology

This study utilized the correlational research design. A correlational study determines whether or not two variables are correlated. This means it studies whether an increase or decrease in one variable corresponds to an increase or decrease in the other variable (Kalla, 2011). Using this research design generated a hypothesis to be proved or disproved, (i.e., whether income or significant other predicts the quality of life of parents with CSHCN). This hypothesis must be provable by mathematical and statistical means, and is the basis around which the whole study is designed.

3. Result and Discussion.

In a total of 107 participants, 89.7% of the respondents are females, with M_{age}=45.27, *SD*=18.49, whereas, only 10.3% are males, with M_{age}=37.97, *SD*=11.02. See table 1.

Most of the respondents are mothers who comprised 78.5%, with M_{age}=34.9, *SD*=7.48; 9.3% are grandmothers, with M_{age}=60.80, *SD*=7.55; 6.5% are fathers, with M_{age}=33, *SD*=7.55; 3.7% are grandfathers, with M_{age}=66.75, *SD*=7.72; and 1.9 % are guardians, with M_{age}=49.5, *SD*=6.36. See table 2.

Among the 107 respondents, 56.1% are married, 26.2% are living as married, 7.5% are widowed, 6.5% are single parents, and 3.7% are separated. In terms of educational background, 55.1% of the respondents have finished secondary, 24.3% have finished tertiary, 19.3% have finished primary, and 0.9% has not received any formal education. See table 3.

Income, which is believed to be a predictor of the quality of life of the respondents, is shown in table 4. The highest income received by a respondent is 21,000 pesos whereas 100 pesos is the lowest. The mean monthly income among the respondents is 3,199.29 pesos and the median monthly income among respondents is 2,000.00 pesos.

Table 1. Gender and Mean Ages of Participants

Gender	Frequency (%)	Mean Age in Years (SD)
Female	96 (89.7)	45.27 (18.49)
Male	11 (10.3)	37.97 (11.02)
TOTAL	107 (100)	38.72 (12.08)

Table 2. Caregiver's Relationship with the Child and their Mean Ages

Caregiver's Relationship to the Child	Frequency (%)	Mean Age in Years (SD)
Mother	84 (78.5)	34.97 (7.48)
Grandmother	10 (9.3)	60.80 (8.24)
Father	7 (6.5)	33.00 (7.55)
Grandfather	4 (3.7)	66.75 (7.72)
Guardian	2 (1.9)	49.5 (6.36)
TOTAL	107 (100)	38.72 (12.08)

Table 3. Marital Status and Educational Attainment of Participants

Marital Status			Educational Attainment		
	Frequency	%		Frequency	%
Married	60	56.1	Secondary	59	55.1
Living as Married	28	26.2	Tertiary	26	24.3
Widowed	8	7.5	Primary	21	19.3
Single	7	6.5	None	1	0.9
Separated	4	3.7			
TOTAL	107	100	TOTAL	107	100

Table 4. Monthly Income of Participants

	Monthly Income (Pesos)
Mean	PHP 3,199.29
Median	PHP 2,000.00
Mode	PHP 2,000.00
Highest	PHP 21,000.00
Lowest	PHP 100.00

Table 5 shows the total number of respondents representing the different barangays from two municipalities of the province of Biliran. Results show that most respondents came from Barangay Binuhangan, (Caibiran), whereas, Barangay Baries (Caibiran), Barangay Katipunan (Caibiran), Barangay Macalpe (Caibiran), and Barangay Tigbao (Caibiran) has one respondent each.

Table 6 shows that among the respondent's children who were identified as having special health care needs, 50.5 % are females, with M_{age}= 8.41, *SD*=5.31whereas 49.5% are males, M_{age}= 8.01, *SD*=5.29. The oldest identified CSHCN for both males and females is 17 years old while 1 year old is the youngest identified CSHCN for both sexes.

Table 7 shows that among the nature of health care needs identified among children of the respondents with special health care needs, 67. 3% are asthmatic, 13.1% are identified as having mental retardation, 6.5% are with cerebral palsy, 3.7% are with down syndrome, 1.9%

are having physical related problems, 1.9% are visually impaired, 0.9% is obese, 0.9% has speech related disorders, 0.9% has heart-related problems, 0.9% has multiple learning disorder, 0.9% has poliomyelitis, and 0.9% has hearing impairment. Most of these CSHCN who availed of intervention is 69.2%, 58.9% are under medication, 42.1% have availed educational programs, and only 2.8% have undergone therapy. It was observed that some of the CSHCN have undergone possible multiple interventions.

Table 5. Barangay of Participants

Barangay	Frequency	Percentage
Binuhangan	36	33.6
Uson	10	9.3
Alegria	8	7.5
Cabibihan	8	7.5
Cuta	6	5.6
Maurang	5	4.7
Palanay	5	4.7
Victory	4	3.7
Kawayanon	3	2.8
Looc	3	2.8
Union	3	2.8
Kaulangohan	2	1.9
Manlabang	2	1.9
Mapapac	2	1.9
P.I. Garcia, Naval	2	1.9
Tomalistis	2	1.9
Palenque	2	1.9
Bariis	1	0.9
Katipunan	1	0.9
Macalpe	1	0.9
Tigbao	1	0.9
TOTAL	**107**	**107**

Table 6. Gender and Ages of the Child

Gender	Frequency (%)	Mean Age in Years (SD)	Mode Age in Years	Highest Age	Lowest Age
Female	54 (50.5)	8.41 (5.31)	5	17	1
Male	53 (49.5)	8.01 (5.29)	3	17	1
TOTAL	107 (100)	8.22 (5.28)	2	17	1

Table 7. Nature of Health Care Needs, Received Intervention, and Type of Intervention.

Nature of Health Care Needs		With Intervention		Type of Intervention	
	Frequency (%)		Frequency (%)		Frequency of YES (%)
Asthma	72 (67.3)	Yes	73 (69.2)	Medicine	63 (58.9)
Mental retardation	14 (13.1)	None	33 (30.8)	In school	45 (42.1)
Cerebral palsy	7 (6.5)			Therapy	3 (2.8)
Down syndrome	4 (3.7)		Possible multiple interventions.		

Physical related problems	2 (1.9)		
Visual impairment	2 (1.9)		
Obesity	1 (0.9)		
Speech related disorders	1 (0.9)		
Heart related problem	1 (0.9)		
Multiple learning disability	1 (0.9)		
Poliomyelitis	1 (0.9)		
Hearing impairment	1 (0.9)		
TOTAL	107 (100)	TOTAL	107 (100)

Table 8 shows the mean scores of participant's quality of life domains: physical (*M*=22.07, *SD*=3.69), psychological (*M*=18.58, *SD*=3.25), social relationships (*M*=11.4, *SD*=2.31), and environment (*M*=24.8, *SD*=4.78)

Table 8. Mean Scores of Participants' Quality of Life Domains

Domains	**Mean (SD)**	**Transformed Scores (0-100)**
Physical Health	22.07 (3.69)	56
Psychological	18.58 (3.25)	50
Social Relationships	11.40 (2.31)	69
Environment	24.8 (4.78)	56
Overall	76.88 (11.69)	

Factors that Predict Quality of Life of Parents/Caregivers of CSHCN

When each perceived social support factor is entered into the regression equation, each significantly predicts the quality of life of parents/caregivers of CHSCN, F_{SOther}=28.19 at p<.01 and it contributes 20.4% to the variance of quality of life, F_{Family}=4.49 at p<.05 and it contributes 3.2% to the variance of quality of life, and $F_{Friends}$=13.41 at p<.01 and it contributes to 10.5% to the variance of quality of life. If we consider the over-all perceived social support score, it significantly predicts the quality of life of parents/caregivers, $F_{OverAll}$=16.47 at p<.01 and it contributes only 12.7% of the variance of quality of life. The results showed that the more social support, the higher the quality of life of parents/caregivers. See table 9.

When the demographic factors are individually entered into the regression equation, only income significantly predicts quality of life of parents/caregivers with CSHCN, F_{Income}=24.01 at p<.01 and it contributes 17.9% to the variance of quality of life. The results mean that the higher the income, the better the quality of life of parents/caregivers. Gender and intervention were not significant predictors to quality of life among parents/caregivers with CSHCN. See table 10.

Table 9. Social support factors that predict Quality of Life of Parents/Caregivers

Factor	F	Adjusted R Square	B	Std. Error	B	T
Significant Other	28.19**	.204	1.73	.325	.460	5.31**
Family	4.49*	.032	.640	.302	.202	2.12*
Friends	13.41**	.105	1.09	.298	.337	3.66**
Over-all	16.47**	.127	.467	.115	.368	4.06**

*p <.05, **p < .01

Table 10. Demographic factors predicting Quality of Life of Parents/Caregivers

Factor	F	Adjusted R Square	B	Std. Error	B	T
Gender	.742	--	--	--	--	--
Income	24.01**	.179	.001	.000	.432	4.91**
Intervention	.026	--	--	--	--	--

** p < .01

When all independent factors were entered into the regression equation, the stepwise regression analysis revealed two models. The first model shows perceived social support from significant other predicts the quality of life of these parents/caregivers, F_{Model1}=28.19 at p<.01, which contributed to 20.4% variance to quality of life. But the second model shows perceived social support from significant others and income predicts the quality of life of these parents/caregivers, $FModel_2$=22.01 at p<.01, which contributed to 28.5% variance to quality of life. Income added 7.1% variance to quality of life. See table 11.

Table 11. Factors that predict Quality of Life among Parents/Caregivers

Model	F	Adjusted R Square	R square change	B	Std. Error	B	T
1	28.19**	.204	--	1.728	.325	.460	5.31**
2	22.01**	.285	.71	1.332	.33	.355	4.01**
				.001	.000	.312	3.59**

*p<.05, **p<.01
Dependent variable: Quality of Life
Model 1: Predictor - Significant Other
Model 2: Predictors – Significant Other & Income

Perceived Social Support from Significant Other as Predictor of Quality of Life

Results of this study showed that among the three perceived social support factors of family, friends, and significant other, the significant other yielded as the highest predictor of quality of life. If each of the factors is entered into the regression equation, each factor significantly predicts quality of life of parents of CSHCN though significant other comes out as the most predictor of parents/caregiver's QOL.

When a child with special health care needs is born into the family, the parents/caregivers experienced stress, which in turn, can influence the quality of life. Social support helps a person navigate through life and is necessary for maintaining the person's physical and emotional well-being (Barutcu & Mert, 2013). Often when the parent/caregiver has physical limitations like sickness or inadequate resources for coping like an absence of someone to listen to their problems, adequate social support becomes particularly important to help parents/caregivers meet their own needs. Parents and caregivers benefit from supportive actions from others as these families of CSHCN face a life long battle with a chronic disorder of communication, behavioral, and socialization difficulties.

In the context of raising a child with special health care needs, studies showed that parents with greater social support show more positive parenting behaviors (Ceballo & McLoyd, 2002) and lower levels of parenting stress (Smith, Oliver, & Innocenti, 2001). Knussen and Slopper (1992) showed that the presence of close social relationship helps parents cope with the stress of raising a child with special health care needs.

There is an increased attention in research on caregiver burden (Baronet, 1999). Caregiver burden is the subjective and objective burden experienced by a caregiver (Idstad, Ask, Tambs, 2010). According to Idstad et al. (2010), subjective burden refers to psychological and emotional distress like feelings of depression and anxiety whereas objective burden includes financial problems. Adult attachment theory (Hazan and Shaver, 1987) will explain why the spouse or the significant other is the first person the caregiver will depend on when he or she experience stress like caregiver burden. It is normal that a parent/caregiver will seek help and emotional support from their spouse and significant other to decrease the subjective and objective burden they feel.

Cellabo and McLoyd (2002) added that because of the lack of formal social supports available in urban communities, the family, to be specific the spouse or significant other, may be a major, if not the only, source of support parents/caregivers of children with health care needs can turn to. In rural areas of the Philippines, such as the barangays in the Municipality of Caibiran and Naval, there are no places where one can spend one’s leisure time considering that there are no malls or other entertainment places to go to, everyone is busy looking for food, and everyone is also busy minding their own problems. A spouse is the only person the caregiver can turn to as his or her partner in life. Therefore, the spouse providing social support (even if it is only perceived by the other partner) to the family serves as a source of joy for the other spouse taking care of the child with special health care needs.

Income as Predictor of Quality of Life

This study also began by asking what socio-demographic factors predict the quality of life of parents with CSHCN. From among the three demographic factors identified in the study as the possible predictor of quality of life, income comes out as the only predictor that predicts quality of life of respondents. This means that the higher the income, the better is the quality of life of the respondents.

Most studies have shown the importance of income for every family particularly on families with children with special health care needs. Financial challenges are considered one of the most common concerns for parents and caregivers of CSHCN (Darbas & Ahmad, 2014). Aside from caregiver burden, taking care of the child with special health care needs can result in enormous economic burden. Results supported other studies showing that family income predicted caregiver’s quality of life, second to family social support (Meral & Cavkaytar, 2012; Cho & Khang, 2014).

Families with higher income have more choices available for them to help them cope when their child needed special health care needs and the daily demands associated with it and have more resources available to deal with issues related to their child's disabilities than do families who have a lower socioeconomic status (Scorgie et al., 1995, Yau & Li-Tsang, 1999; Turnbull & Turnbull, 2001).

For Filipino families, income is considered a source of life. Without money, one cannot buy anything. In a way, income gives parents hope to hold on to life because, through money, they still have means to do so. This includes their willingness to continue caring for a CSHCN despite the stress it brings to their life. Almost all respondents in this study claimed of hoping and wishing to have a bigger income in order to support all their needs especially money for food and medicine. Income, according to them, is a source of inspiration and joy. Without money life is miserable and hopeless.

Results of this study are quite interesting because factors predicting the quality of life of parents/caregivers with CSHCN are the perceived social support of the significant other and income. In the Philippines, these two factors are intertwined for most couples considering that one goes without the other. Because most respondents claimed that the higher the income they have, the better is their quality of life. It means the support coming from the spouse is astounding. This is because the one providing for the income is the spouse himself or herself leaving the other spouse caring for the child with special health care needs. If these two factors go together then there is no reason why the quality of life of a person will not get better.

3. Conclusion.

Children are considered the source of joy of every parent. Although every parent expects the best for an incoming family member it cannot be denied that some failed that expectations. There are just children who are born different from what is considered normal in our society. Nevertheless, these are still individuals who have life, a soul which may be considered different but special, and a heart that needed to be felt by everyone.

These children just like their parents are special. When we say special we do not mean to degrade, insult, or limit their capacity to be human beings but rather a point that gives someone to consider especially in dealing with them. Parents and or caregivers are the most vulnerable when it comes to parenting children with special health care needs. What everyone can do is to extend support to them in whatever way they can in order to make these parents/caregivers feel they are not alone and that everyone is also concerned of their welfare and well-being. Social support is what the parents/caregivers need.

In the light of the results of this study, it can be suggested that the higher the levels of social support, the higher the parent’s quality of life. This means that support provided to parents should be increased through programs and services offered by the government. It is important to provide support for families because CSHCN receive most of the support from their families. In order to protect parents/caregivers’ bio psychosocial health, they should be helped to tolerate the burden of care, by providing them training on such topics as stress, coping strategies, and effective communication skills when dealing with CSHCN.

Since social support plays a great role in the improvement of quality of life, parents and/or caregivers should find ways to activate the sources of support and to direct them. Sources of support from outside the family should be activated. Health professionals, psychologists, occupational therapists, psychiatrists, and other professionals who are experts in this field may include in their programs, services that will cater to the needs of the parents.

A Primary-Coach Approach to teaming and supporting families in early childhood intervention may be utilized. This approach is implemented when an early intervention program is identified as a formal resource for early childhood intervention and family support. Also, this program employs or contracts with practitioners with diverse knowledge and experiences to support the child’s parents and other primary care providers.

Since income in this study is also found to be a predictor of a parent/caregiver’s quality of life, what the government can do is to provide not just financial assistance like *pantawid-buhay* to these parents but to ensure that at least one spouse of every family has a stable means of income. This can be done through programs which should be extended by *DSWD* and other agencies like Technical Education and Skills Development Authority or *TESDA* that will develop skills these people already have through livelihood programs.

So much can actually be done if only the heart of those who seat in the government are voracious not in taking money from the poor but in providing its people especially the vulnerable ones enough means to support themselves. Humanity is at stake if those who are supposed to be responsible in taking care of the sanity and health of the people of the Republic of the Philippines like the Department of Health or *DOH* will act early on to provide interventions before the extinction of the healthy people will come. The high prevalence of CSHCN in the municipality of Caibiran alone is already an indication that something is wrong in the environment and the government has not done anything to address them. The plight of the parents who have children with special health care needs in this area is overwhelming and they needed all the support they could get from their spouses, families, friends, and from the different agencies of the government, if only to hold on to this life not just for their own sake, but most importantly, for the sake of the children with special health care needs who are in their care.

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