

QUALITY OF LIFE OF SIBLINGS OF CHILDREN WITH DISABILITY

Ivan Neil B. Gomez^{1,2}, Mara Stefanie De Leon², Carmela Loisaga², Raquel Magpantay², Cristina Mallari², Jieuben Rosario²

Abstract: Background: Previous studies have explored how a child with disabilities can affect their family's well-being. However, there is limited inquiry addressing the quality of life among siblings of children with disability. **Objective:** This study aimed to describe the quality of life of siblings of children with disability and to identify the domain-based quality of life issues siblings of children with disabilities face. **Methods:** Sixty siblings of children with disability between the ages of 12-18 were recruited and answered the WHOQOL-BREF Filipino version. **Results:** The overall quality of life of the participants showed a mean of 3.01, which is neither poor nor good (average). The domain-related scores of the participants were within the average range: Domain 1 (Physical Domain)= 3.52, Domain 2 (Psychological Domain)= 3.57, Domain 3 (Social Relationships)= 3.59, and Domain 4 (Economic Domain)= 3.06. **Conclusion:** The current study showed that the quality of life of siblings of children with disability is neither poor nor good (average), which may indicate that they may be well adjusted with their conditions. Future research is recommended to replicate and corroborate these findings in a larger population, as well as a qualitative inquiry to the issue.

Keywords: quality of life, sibling, children, disability, well-being

INTRODUCTION

Children with disabilities require more parental attention and care, and overall healthcare compared to their typically-developing peers or siblings (Goudie et al., 2013; Stoneman et al., 2005). The long-term and challenging task for raising a child with a disability can affect the family's function (Reichman et al., 2008). The burden of care may result in various psychological reactions related to shock, depressions, anger, guilt, disappointment, and filial discord (Giallo et al., 2014). Over time, these reactions may be ingrained within the family's dynamics, consequently affecting their health, well-being, and quality of life. The family is placed in a critical position where adaptation is needed to function for itself and the child with a disability (Gomez & Gomez, 2013) optimally. Inflexibility, in adapting to the changing roles and functions within the family, may influence the siblings' well-being (Goudie et al., 2013).

¹Center for Health Research and Movement Science, College of Rehabilitation Sciences, University of Santo Tomas

²Department of Occupational Therapy, College of Rehabilitation Sciences, University of Santo Tomas

The theoretical framework basis of this study is grounded on the transactional model of family stress (Lazarus & Folkman, 1984), and the quality of life model adopted from the World Health Organization (WHO, 1998). The birth of a child with a disability into the family presents a lifelong challenge, which may be characterized as a stressful event (Gomez & Gomez, 2013; Lazarus & Folkman, 1984). A child who has a disability in the family can pose significant emotional challenges for their typically-developing siblings. These siblings of children with disability (SCWD) experience feelings of isolation, guilt, resentment, perceived pressure to achieve, increased caregiving demands, sense of embarrassment and ostracism by their peers, and concerns about their role in their sibling's future (Dyke et al., 2008; Meadan et al., 2010). In some cases, the behavioral symptoms of the child with a disability may be directed towards the SCWD. They not only experience stressful life situations, but they also revealed experiences of fear from being victims of violent behaviors of their sibling with disability (Green, 2013; Meadan et al., 2010).

Moreover, the looming provision of support to the child with a disability in the future as eventual caregivers creates a significant impact on the well-being of the SCWD. The amount of actual help from siblings in rearing the child with disability increased as parents became less available to provide support, which may result in adverse effects such as experiencing feelings of loneliness and low levels of pro-social behavior (Green, 2013; Horwitz, 1993). This is further aggravated by concerns on the economics of raising a child with a disability. The non-disabled sibling must adjust to a brother or sister who, because of their condition, may require a large portion of the money and financial support. Financial challenges significantly affect family functioning, and cost of care for a child with a disability can have profound effects on the SCWD's health, productivity, physical environment, emotional well-being, and family interaction (Dyke et al., 2008; Fujira & Yamaki, 1997; Park et al., 2002).

Quality of life (QOL) pertains to an individual's perception of how good their life is within the context of their environment and values, in relation (WHOQOL Group, 1994, 1995). This definition reflects the view that QOL refers to a subjective evaluation that is embedded in a cultural, social, and environmental context. It is a broad-ranging concept affected in a complicated way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment. QOL can be indexed using various measures and methodologies. One of the more conventional means of reporting QOL outcomes is using the WHOQOL-BREF (WHO, 1998). The WHOQOL-BREF produced a QOL profile wherein it is possible to derive four domain scores. Two items are examined separately: question 1 asks about an individual's overall perception of the QOL, and question 2 asks about an individual's overall perception of their health. The four domain scores denote an individual's perception of the QOL in each particular domain. Domain scores are scaled in a positive direction (i.e., higher scores indicate a higher QOL). The domains and their corresponding facets are outlined in Table 1.

Table 1. Summary of QOL domains and corresponding facets on the WHOQOL-BREF.

Domain	Facets of 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	Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory, and concentration Bodily image and appearance
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

Numerous studies have already looked at how raising a child with a disability can affect the family's QOL. However, the focus on the QOL of SCWD has been sparse or at best conflicting (Green, 2013; Meadan et al., 2010; Smith & Elder, 2010), especially within the Philippine context. The SCWD may have problems themselves overlooked by the family whose focus is on the child with a disability. We hypothesize that these SCWD may have poor QOL. While existing services are available to the child with a disability and their parents, these may not be readily accessible for the SCWD. Built on this rationale, we believe that it is imperative to investigate these aspects to identify the specific support systems they need. In this research, we report on the survey we conducted among SCWD and their QOL. We aimed to describe the QOL of SCWD and identify their domain-based QOL issues.

METHODOLOGY

The researchers employed a descriptive study using a cross-sectional quantitative method to describe the QOL of SCWD. Ethical approval was sought from then the Ethics Committee of the University of Santo Tomas- College of Rehabilitation Sciences before data collection. Written informed consent was obtained before the conduct of the study from the participants and their parents, whichever may have been applicable in their condition.

Participants

We recruited $n= 60$ SCWD using a non-random purposive sampling technique within Metro Manila. They have no history of psychiatric or neurodevelopmental disability as per self-reported and confirmed with their parents. The participants were between the ages of 12-18 years old and are currently living with their sibling with a disability. The minimum educational attainment of primary school was set to ensure that the participants understand the instructions and the contents of the questionnaires.

Instrumentation and Procedures

This study used the WHOQOL-BREF as its primary tool to measure the QOL of SCWD. The WHOQOL-BREF is a self-administered instrument that comprised of 26 items, which measured the following broad domains: physical health, psychological health, social relationships, and environment (WHO, 1998). Scoring is based on a 5-point scale basis (5 is interpreted as very good; 4 is good, 3 is neither poor nor good/average; 2 is poor; 1 is very poor). Domain scores are scaled in a positive direction. The higher scores denote a higher QOL. Only 24 out of 26 questions assess the QOL in the different domains. Question 1 is a general question that assesses overall QOL, while question 2 determines the individual's general health. The WHOQOL-BREF has been proven to be a valid and reliable instrument in measuring QOL (Skevington et al., 2004; Skevington et al., 2014). In this study, we used the Filipino version of the tool, administered using the original pen and paper format. While there is no published evidence on the validity of the Filipino version, the tool has undergone the strict procedures for translation by the WHO. It has been used in a previous related study (Gomez & Gomez, 2013).

The participants were recruited through various rehabilitation institutions across Metro Manila. We invited the SCWD through their parents. After obtaining informed consent, the parents, and when possible, the SCWD, were provided instructions on how to answer the WHOQOL-BREF. The participants were given a chance to clarify issues related to the conduct of the study and the process of answering the questionnaire, and if any case they had further questions, the contact details of the authors were indicated in the forms for them to contact and be given clarifications. Generally, the siblings were instructed to answer the items on the WHOQOL-BREF and the data collection form based on how they responded to the questions within the last two months. The participants were given one week to accomplish the questionnaires before returning them to the researchers. A minimum questionnaire response set of 80.00% was placed to determine the eligibility of the questionnaires. Whenever possible, the researchers contacted the participants to collect additional for missing information.

Data Analysis

In the analysis of the data, we used percentages and mean scores to present the data in this study. We tallied the responses of the siblings using a custom-built MS Excel data spreadsheet. Scores on the WHOQOL-BREF were computed based on the recommended procedures (WHO,1998) of averaging the responses for Questions 1 and 2, and the four domains of the questionnaire. We used the syntax formula for the calculation of scores on the WHOQOL-BREF using SPSS 16, along with computing for descriptive statistics.

RESULTS

Participant Characteristics

Sixty SCWD, 66.00% female, were recruited in this study, having a mean age of 15.43 years. Their sibling with a disability, 51.67% female, had a mean age of 12.16 years. Fifty-five percent of the siblings with a disability were reported to have a mild disability, with a majority of them attending school (61.67%) and receiving therapeutic services (61.67%). The majority of the participants belong to one parent working household (96.67%), highest educational attainment was a secondary school (53.33%), and a monthly income of <PhP10,000. A more salient summary of the participant characteristics is reported in Table 2.

Table 2. Background characteristics of the siblings of children with disability and their families (n= 60).

Characteristics		n	%
Sibling Without Disability	Gender		
	Male	20	33.00%
	Female	40	66.00%
	Age		
	18 years old	15	25.00%
	17 years old	6	10.00%
	16 years old	11	18.33%
	15 years old	8	13.33%
14 years old	6	10.00%	
13 years old	6	10.00%	
12 years old	8	13.3%	
Sibling With Disability	Gender		
	Male	29	48.33%
	Female	31	51.67%
	Age		
	1 to 5 years old	4	6.67%
	6 to 10 years old	23	38.33%
	11 to 15 years old	13	21.67%
	16-20 years old	15	25.00%
	> 20 years old	5	8.33%
	Severity of disability		
	Mild	33	55.00%
	Moderate	22	36.67%
	Severe	5	8.33%
	Attends school		
Yes	41	68.33%	
No	19	31.67%	
Undergoing therapy			
Yes	37	61.67%	
No	23	38.33%	
Years in therapy			
Not Sure	35	58.30%	
1 year or less	2	5.40%	
2-5 years	17	45.94%	
6-10 years	6	16.21%	

Parental And Household Status	Parents have work		
	Yes	58	96.67%
	No	2	3.33%
	Highest Educational Attainment	8	13.33%
	Elementary	32	53.33%
	High School	0	
	Vocational	21	35.00%
	College		
	Monthly Income of family		
	10K below	31	51.67%
11K-50K	0		
51K-150K	25	41.67%	
151K-300K	0		
301K-500K	4	6.67%	

Overall and Domain-Based Quality of Life

The overall and domain-based QOL scores of the participants on the QOL-BREF are summarized in Table 3. The overall QOL item shows a mean of 3.01 (neither poor nor good; average). The general health item shows a mean of 3.32 (slightly above the average). Among the four QOL domains, Domain 4 (Economic domain) has the lowest rank at 3.06, followed by Domain 1 (Physical Domain) at 3.52, then Domain 2 (Psychological Domain) at 3.57 and Domain 3 (Social Relationships Domain) at 3.59 at the highest rank.

Table 3. Quality of life status of the siblings of children with disability (n= 60).

Domain	Mean Raw Scores on the WHOQOL-BREF
Overall QOL	3.01
General Health	3.32
Domain 1: Physical	3.52
Domain 2: Psychological	3.57
Domain 3: Social Relationships	3.59
Domain 4: Economic	3.06

DISCUSSION

Based on our results, SCWD had an average QOL, general health, and domain-related QOL. Their condition and contexts do not negatively affect their physical health, psychological functions, social relationships, and mastery of their physical environments. These results were not far from previously reported QOL among parents of children with disability (Gomez & Gomez, 2013). Although it may be assumed that SCWD has poor QOL as earlier hypothesized, the results of this study show that their QOL is neither poor nor good. There might be several reasons to explain this phenomenon.

On the one hand, this research is constrained with the statistical population recruited in this study. Future research aiming to replicate and corroborate our findings is recommended to recruit a more robust sample derived from theoretically-driven sample size and less varied characteristics within the sample. On the other hand, our results may embody the previously suggested conflicting nature of QOL among SCWD (Green, 2013; Meadan et al., 2010; Smith & Elder, 2010). That is, some siblings may view their QOL as lower, while others see it otherwise.

QOL, as a construct, is dependent on the individual’s perception of their lives. While there is evidence for us to assume that living with a child with a disability is stressful, there might be positive effects to this (Gomez &

Gomez, 2013). One's appraisal of their situation may mitigate how they view their condition (Lazarus & Folkman, 1984). The positive feelings associated with being an SCWD has been reported previously. These include the development of positive personality characteristics of a caring and compassionate nature; increased maturity compared to their peers; and an enhanced appreciation of their health and abilities (Beyer, 2009; Meadan et al., 2010). SCWD may be well adjusted than we give them credit for, except for some extreme cases (Green, 2013). Nevertheless, we approached QOL in this research from a quantitative perspective. The qualitative information behind the lived experiences of SCWD is beyond the scope of this study. Qualitative research in the same areas has revealed an opposing picture (Green, 2013). While they may be reporting to behave and cope well, a consequent hidden issue arising from an inner turmoil might be brewing. An in-depth examination of this matter is recommended.

Siblings represent a fraction of the family, and their QOL might be related to other members of their family. When compared to a similar study (Gomez & Gomez, 2013), we find similar trends between the QOL of SCWD and those with the parents using the WHOQOL-BREF. The QOL of parents of children with special needs were within the average range (3.24 - 3.82), although higher. The developmental advantage of parents compared to the siblings may provide a laudable explanation on this. The experiences of parents of children with disability have enabled them to develop a coping mechanism, which allows them to be positive, optimistic, and hopeful in their contexts (Peer & Hillman, 2014). Resilience among families has been described in the literature as a mediating factor against stress and is commonly seen among mothers (Levine, 2009; McConnel & Savage, 2014). It may very well be that family support and nurture for the SCWD could have mitigated the otherwise negative effect of raising a child with a disability. This goes beyond the intended purpose of this study. Hence the authors recommend further studies on this matter.

CONCLUSION

This study investigated the QOL of SCWD. Our results indicate that the overall QOL of siblings of children with disability is perceived as average. The QOL of SCWD per domain (physical, psychological, social, economic) is likewise ascertained to be neither good nor poor and lies within the average range. It seems that SCWD are adjusted to their conditions. Future research on this matter should replicate this study in a larger population and explore on the qualitative aspects of QOL among SCWD.

ACKNOWLEDGMENT

The authors would like to acknowledge the help of the various institutions, parents, and participants of this study.

REFERENCES

- Beyer, J. F. (2009). Autism spectrum disorders and sibling relationships: Research and strategies. *Education and Training in Developmental Disabilities*, 444-452.
- Dyke, P., Mulroy, S., & Leonard, H. (2009). Siblings of children with disabilities: Challenges and opportunities. *Acta Paediatrica*, 98(1), 23.
- Fujiura, G. T., & Yamaki, K. (1997). Analysis of ethnic variations in developmental disability prevalence and household economic status. *Mental Retardation*, 35(4), 286-294.
- Giallo, R., Roberts, R., Emerson, E., Wood, C., & Gavidia-Payne, S. (2014). The emotional and behavioural functioning of siblings of children with special health care needs across childhood. *Research in Developmental Disabilities*, 35(4), 814-825.
- Gomez, I. N. B., & Gomez, M. G. A. (2013). Quality of life of parents of filipino children with special needs. *Education Quarterly*, 71(2).
- Goudie, A., Havercamp, S., Jamieson, B., & Sahr, T. (2013). Assessing functional impairment in siblings living with children with disability. *Pediatrics*, 132(2), e476-e483.
- Green, L. (2013). The well-being of siblings of individuals with autism. *ISRN Neurology*, 2013.
- Horwitz, A. V. (1993). Siblings as caregivers for the seriously mentally ill. *The Milbank Quarterly*, 323-339.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.

- Levine, K. A. (2009). Against all odds: Resilience in single mothers of children with disabilities. *Social Work in Health Care, 48*(4), 402-419.
- McConnell, D., Savage, A., & Breitzkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities, 35*(4), 833-848.
- Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 22*(1), 83-100.
- Park, J., Turnbull, A. P., & Turnbull III, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children, 68*(2), 151-170.
- Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92-98.
- Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal and Child Health Journal, 12*(6), 679-683.
- Skevington, S. M., Dehner, S., Gillison, F. B., McGrath, E. J., & Lovell, C. R. (2014). How appropriate is the WHOQOL-BREF for assessing the quality of life of adolescents?. *Psychology & Health, 29*(3), 297-317.
- Skevington, S. M., Lotfy, M., & O'Connell, K. 2. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of Life Research, 13*(2), 299-310.
- Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing, 23*(3), 189-195.
- Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation, 43*(5), 339-350.
- WHOQOL Group. (1994). Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health, 23*(3), 24-56.
- WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social science & medicine, 41*(10), 1403-1409.
- WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*(3), 551-558.